YOUNG AUTISTIC ADULTS: TRANSITION PRACTICES, SELF-DETERMINATION, AND POST-SCHOOL QUALITY OF LIFE

A Thesis submitted by

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ABSTRACT

The purpose of this proposed research was to describe the perceptions of young autistic adults, and their parents, regarding the transition practices implemented during their secondary education. The impact of these practices on the young adults' post-school quality of life (QoL) was also considered. Transition practices are implemented for all students in Queensland secondary schools and are recommended as a guide for the student's education, ensuring that it focuses on preparing students to make a successful transition from school to post-school options. Considering the very specific challenges experienced by young autistic adults in achieving good QoL after school, the effectiveness of current transition practices for autistic students in Queensland schools were unknown. The proposed research was conducted within an overarching theoretical framework of self-determination theory (Deci & Ryan, 2002), while considering the interconnectedness of transition practices and post-school QoL through the well-established and research-based frameworks; Kohler's (1996) Taxonomy for Transition Programming, and Schalock's (2004) Quality of Life indicators. A multiple case study design was used to gather qualitative data from young autistic adults who have made the transition from secondary school to post-school options, and their parents, in Queensland. This research provided a valuable understanding into the relationship between current transition practices and post-school QoL, thus providing a key step in the ongoing evaluation and improvement agenda for Queensland secondary schools. The findings of the proposed research contributed to an understanding of the applicability of these frameworks, and also provided practical knowledge to all stakeholders involved in school to post-school transitions for autistic adolescents and young adults.

CERTIFICATION OF THESIS

I, Karen Glasby, declare that the Doctor of Education Thesis entitled Self-determination for the rest of my life: young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life is not more than 152,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references, and footnotes (by agreement with supervisors and examiners). The thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Signed: Date:

Endorsed by:

Professor Patrick Danaher
Principal Supervisor

Dr Kay Ayre
Associate Supervisor

Student and supervisors' signatures of endorsement are held at the University.

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ABBREVIATIONS

ABS	Australian Bureau of Statistics
APA	American Psychological Association
ASPECT	Autism Spectrum Australia
ASD	Autism spectrum disorder
DDA	Disability Discrimination Act
DSE	Disability Standards for Education
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders (IV)
DSM-5	Diagnostic and Statistical Manual of Mental Disorders (5)
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual disability
IDD	Intellectual and developmental disability
IQ	Intelligence quotient
LD	Learning disability
NDIS	National Disability Insurance Scheme
QoL	Quality of Life
SDT	Self-determination Theory
SET	Senior Education and Training (plan)
TAFE	Tertiary and Further Education
TTP	Taxonomy for Transition Programming
UNCRPD	United Nations Convention on the Rights of People with Disabilities
WHO	World Health Organization

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CHAPTER 1: INTRODUCTION

1.1. Chapter Overview

The transition from school to post-school is a significant time of change for any young person as they move from adolescence to life as an adult. For young people on the autism spectrum, this period of transition from school to post-school is increasingly recognised as one that is challenging and that often results in poor quality of life (QoL) (van Heijst & Geurts, 2015). QoL refers to the set of factors that make up an individual's wellbeing and is defined by the World Health Organisation (1995) as "the individual's perception of his or her position in life in the context of the culture and value system, and in relation to one's goals, expectations, standards, and concerns" (p. 1405). The concept of QoL for people with developmental disabilities was introduced in the 1980s following the movement of normalisation or supporting people with developmental disabilities to live as close to a normal life as possible (Schalock, 2000). For people with developmental disabilities such as autism, the appeal and strength of the QoL concept lie in its values of "equity, inclusion, self- 61 determination and empowerment, and its focus on the individual" (Schalock, 2020, p. 2). QoL emphasises a holistic view of the person and is focused on the person's overall wellbeing.

In particular, the period of young adulthood is one where individuals are expected to take what they have learned throughout their childhood and adolescence and apply these skills, knowledge, and attitudes to adulthood. Typically, this successful application results in independent functioning, high levels of responsibility and contribution to society across many areas, indicating a good QoL. Educational contexts are key contributors to this development of skills, knowledge, and attitudes, and thus, play a key role in this transition process and the experience of adulthood. This study used a case study approach to investigate the perceptions of young autistic adults about the interaction between Queensland secondary school transition practices and QoL in young adulthood.

This chapter introduces the research problem while establishing the context and significance of the problem. This is achieved through a discussion of autism and its implications for schooling and transition. Current transition practices and how these provide support for the needs of autistic individuals are also addressed. The research questions are introduced, and a brief description of the research approach is presented. I, as the researcher discuss my personal positioning in relation to the study and the decisions behind the strengths-based approach and language used throughout the thesis. An overview of the thesis is presented with a summary concluding the chapter.

1.2. The Context and Significance of the Problem

1.2.1. Autism

Autism spectrum disorder (ASD) is a lifelong neurobiological disorder that is characterised by impairments in social communication and restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). According to the Diagnostic and Statistical Manual of Mental Disorders 5th edition DSM-5 (American Psychiatric Association, 2013), the social impairments characteristic of autistic people may include difficulties in the areas of social interaction including social-emotional reciprocity, nonverbal communicative behaviours and developing, maintaining, and understanding relationships. The restricted, repetitive patterns of behaviour may include repetitive motor movements, an insistence on sameness, inflexible adherence to routines, ritualised patterns of verbal or nonverbal behaviour, highly restricted, fixated interests, and hyper or hyposensitivity to sensory input (American Psychiatric Association, 2013). The severity level of these impairments varies significantly for each individual and the impact that they have on the individual's level of functioning is also highly variable. While some autistic people have a dual diagnosis of autism and intellectual disability (ID), many have average or above-average intelligence.

More contemporary views of autism have moved away from the medical model described above, instead focusing on autism as a natural form of human diversity that "affects how a person thinks, feels, interacts with others and experiences their environment" (Autism Spectrum Australia, n.d.). Within this natural form of human diversity, the term ***impairment*** is not used; rather, the differences between how autistic and non-autistic people communicate, socialise, and behave are emphasised, with neither seen as being impaired or wrong. Thus, instead of these differences being viewed as a form of deviance that must be corrected, they are viewed as appropriate and functional within environments that recognise and support diversity and difference (Bottema-Beutel et al., 2020; Leadbitter et al., 2021). From this perspective the term ***autism spectrum disorder*** is not accepted by autistic advocates, as being autistic is not considered to be a disorder. To avoid the continuation of the deficit discourse of autism being recognised as a disorder, the term ***autism*** is used throughout the remainder of this study (Bottema-Beutel et al., 2020).

Despite these more contemporary views of autism and the positive implications for people on the spectrum, research continues to find that autistic individuals experience poor academic and social outcomes throughout their schooling and, as a result, poor post-school outcomes in adulthood (Flower et al., 2021; Hay & Winn, 2012; Hume et al., 2014). Data presented by the Australian Bureau of Statistics (ABS) supported these findings. The Survey of Disability, Ageing and Carers (SDAC) (Australian Bureau of Statistics [ABS], 2019) findings indicated that over 30% of autistic young people’s highest level of education is Year 10 or below, more than twice the rate of nonautistic young people, with nearly 45% having their highest level of education being Year 12 (Australian Bureau of Statistics [ABS], 2019). Furthermore, young autistic people are more than a third less likely to complete a bachelor degree or higher and approximately half as likely to receive a diploma or a certificate after secondary school. Comparing these data to those of nonautistic young people and young people with other disabilities, autistic individuals experience some of the lowest educational attainment levels in Australia.

These low educational attainment levels, combined with the characteristics of autistic people and the disadvantage that they experience in post-school settings, result in similarly poor outcomes in adulthood. ABS data (2019) found that employment for people on the autism spectrum was only 38%, compared to 53.4% for people with other disability and 84.1% for people without disability. With this, the unemployment rate for autistic individuals was 34.1 %, for people with disability it was 10.3%, and for people without disability it was 4.6%. From these data, autistic adults living in Australia are more than three times more likely to be unemployed than people with other disabilities, and nearly eight times more likely to be unemployed than people without disability. Furthermore, those adults who are employed are more likely to be underemployed, meaning that they do not work as many hours as they would like, or that they are working in jobs beneath their education level (Flower et al., 2021). These data are not unique to Australia, with findings from the United Nations (United Nations Deparment of Public Information, 2015) estimating that more than 80% of autistic adults are underemployed or unemployed.

Living circumstances are also an area where autistic adults experience disadvantage. Buescher et al. (2014) reported that 79% of autistic adults without a co-occurring ID lived in the family home, and that 48% of autistic adults with ID lived at home. For individuals with autism and ID, 24% lived in residential care facilities and 27% in supported accommodation. Cakir et al. (2020) reported that approximately only 17% of young autistic adults lived independently, and Hewitt et al. (2017) suggested that the number of autistic adults living at home continued to increase, especially for people under the age of 30. These statistics on independent living were further supported by ABS data (Australian Bureau of Statistics [ABS], 2019) finding that 68.9% of all people on the autism spectrum reported that they require support for core activities such as communication, self-care, and mobility, and that 73.3 % required support for cognitive or emotional tasks. Despite this, over 50% of people on the autism spectrum stated that they did not receive as much assistance as was needed to meet their needs. Additionally, it is important to note that the significant majority of all supports provided to autistic individuals are informal, that is, provided by relatives or friends (Australian Bureau of Statistics [ABS], 2019).

Considering the above discussion and aligning this with prevalence data, the magnitude of this societal problem can be seen. The most recent estimates of autism prevalence in Australia by the ABS (2019) indicated that, in the year 2018, over 205,000 Australians were diagnosed with autism, a 25.1% increase from 2015. This increase is likely to have continued since 2018, as the ABS (2019) demonstrated that the prevalence of autism diagnosis is continuing to increase. Thus, a significant proportion of young adults and their families are likely to be experiencing social, emotional, and financial disadvantage in our current Australian society.

1.2.2. Adulthood

In Western societies such as Australia, the late teens and early twenties are a time of great change as young people move from the period of adolescence to adulthood. This period typically starts at around 18 and goes until 25 years of age, coinciding with completing secondary school and moving into adult roles such as tertiary study, employment, moving out of the family home, and developing new and different relationships (Arnett, 2014). Arnett (2014) went on to describe this period as being a self-focused time of identity exploration that involves much instability and feeling in-between, while also being a time of experiencing great possibilities. During this period, most emerging adults focus on developing or enhancing the knowledge, skills, and self-understanding needed for adult life, with a strong emphasis on independence, or "learning to stand alone as a self-sufficient person without relying on anyone else" (Arnett, 2014, p. 14). From the young adults' perspective, this means accepting responsibility for oneself, making independent decisions, and becoming financially independent.

As with all individuals in Western societies such as Australia, the transition to adulthood occurs when the young person turns 18 years of age. It is at this point that the young person is legally considered an adult and can engage in many behaviours that are considered to define adulthood such as voting and signing legal documents. More implicitly, once young people have turned 18, they are often expected to start moving towards leaving the family home, being independent in their decisions, supporting themselves financially, and beginning to contribute to their wider society (Arnett, 2014). For people on the autism spectrum, this move to adulthood is less defined. While they are legally considered adults at 18, it is suggested that young people on the spectrum rarely engage in the behaviours described above, instead continuing to live with and rely on their parents for social, emotional, and financial support (Mattys et al., 2018).

1.2.3. Education

Educational settings in Australia, particularly secondary schools, have the capacity to help to prepare all students for their future as adults and to positively influence post-school outcomes. It is recognised that, as part of a shared community responsibility; between schools, parents, students and the broader community, schools play a vital role in shaping the development of young people and have an obligation to provide young people with the skills, knowledge, and attitudes that they need to function successfully as adults in our society (Education Council, 2019). While this vision may underpin educational contexts throughout the country, there are still many groups of young people who fail to reach their potential as they transition from school to post-school options, and who struggle to attain the QoL in adulthood that meets this vision. Young autistic adults are one such group (Marsack-Topolewski & Maragakis, 2021).

1.2.4. Transition

Stated simply, the research problem explored in this thesis is that a large proportion of young autistic adults' finish school without the skills, knowledge, and attitudes needed to transition successfully into post-school life options such as tertiary education, employment, engagement with support services, and decisions regarding independent living and financial wellbeing. This lack of skills, knowledge, and attitudes results in a significant number of young autistic adults experiencing poor post-school outcomes (van Heijst & Geurts, 2015) which relate to all areas of life including independent living, employment, further education and training, interpersonal relationships, community participation, and psychological and emotional wellbeing (Hay & Winn, 2012). For many young adults on the autism spectrum, life after school looks like: living at home with their parents or carers; not engaging in further education or training; being unemployed; and having few personal or community contacts other than with those who live in the same home. As for any person, this life of isolation typically results in increased levels of psychological difficulties, including depression, anxiety, and decreased overall psychological and physical wellbeing (Maitland et al., 2021). It has also been found that these post-school outcomes further exacerbate the underlying characteristics of autism: social communication differences; and rigid and repetitive behaviours, interests, and activities (Marsack-Topolewski & Maragakis, 2021). Thus, the cyclical nature of the underlying characteristics and poor QoL at this point of transition can result in long-term QoL difficulties.

The negative outcomes for young autistic adults not only impact on the young people themselves but also generate documented negative outcomes for the families of these young adults. Raff et al. (2021) found that parents of autistic individuals who are transitioning from school to post-school options experience higher levels of stress, anxiety, and depression than parents of their typically developing peers, or parents of young adults with other disabilities or differences. These higher levels of stress and anxiety are directly related to the fear surrounding the transition process, and to an understanding that the core characteristic differences experienced by their autistic child will make engaging in the typical activities and processes required at this point of transition difficult (Cheak-Zamora et al., 2015). Parents of young autistic adults recognise the critical need for social and communication skills in the workforce. They understand the difficulty that the young person has around accepting and adapting to new routines and expectations, and the adaptive skills required for independent living.

As a result of this understanding, many parents of young autistic adults who are about to transition from school to post-school options, become the key stakeholders in supporting their young adult to learn the skills, knowledge, and attitudes required to make this transition as successful as possible. The expectations for these parents are significantly more than for parents of typically developing young adults or for adults with other disabilities or difference (Siracusano et al., 2021). For most parents, the need to advocate for and support their young autistic adult, in turn, results in reduced employment opportunities, increased financial responsibilities, and decreased social and emotional wellbeing (Cakir et al., 2020; Horlin et al., 2014; Walsh et al., 2021). Many parents, for no reason other than the needs of their adult child, also find themselves isolated from family and friends, unemployed or struggling to maintain employment, struggling financially, and unable to engage with or to access personal or community support. Similarly to the young adult, this results in overall poorer levels of psychological and physical health and wellbeing for the parents and carers, and often the siblings, of the young autistic adult (Kurzrok et al., 2021; Walsh et al., 2021).

These significant impacts are experienced by the young autistic adult, the parents/carers, and families, as well as the broader community and society. Research conducted by Horlin et al. (2014) estimated that a diagnosis of autism results in an estimated annual cost to Australia of $4.5 - $7.2 billion, with this cost estimated to increase in future generations. These costs result from lost income from the autistic individual and their parents/carers, medical and health-care costs, education costs, and costs associated with care giving, living, and rehabilitation services (Rogge & Janssen, 2019). Furthermore, the social costs of autism are found to increase across the lifespan. That is, costs increase as the young person moves from childhood and adolescence into adulthood (Rogge & Janssen, 2019), with the largest direct life-time cost found to be providing care for autistic adults (Horlin et al., 2014). With a recognition that the number of autistic individuals moving from childhood services to the adult service system is steadily increasing (Hewitt et al., 2017), the costs of failing to provide appropriate opportunities to autistic individuals are significant.

From this evidence, supporting young autistic adults to transition successfully from school to post-school options should be a key concern for everyone in Australian society, that is, parents and carers, educators, employers, service providers, and governments. It is well documented in educational research that schooling experiences and life outcomes are strongly linked (Parsons, 2015). Although the causal relationships between education and life outcomes are complex, interactive, and multi-layered, education is seen as playing a key role in preparing children and youth to become active and informed citizens who experience wellbeing across various life domains (Education Council, 2019). Within this wide scope of education, transition programs are, or transition-focused education is, considered to be particularly important for supporting positive adult outcomes, and considered to be even more crucial for students who experience disability such as those on the autism spectrum (Kohler, 1996; Kohler & Field, 2003).

1.2.5. Transition Practices

Current Qld mainstream secondary school transition practices mean that autistic students are offered similar transition programs to their peers. The Queensland Department of Education requires students in schools to complete a Senior Education and Training (SET) plan during Year 10 (Queensland Government, 2021c). The SET plan assists students, parents, and the school to "map out a plan of action to ensure students remain on track for success in senior secondary, post-school education and work" (Queensland Government, 2021c, p. 1). During the period of SET planning, schools are required to provide skill development sessions to support students in thinking about their careers. Furthermore, students are encouraged to work with their parents in making these final decisions. The SET planning procedure (Queensland Government, 2021c) recommends that school staff "consider the need for more targeted and intensive transition strategies and support for students with disability" (p. 2). There are, however, few resources and limited professional development opportunities for Queensland Department of Education school staff providing guidance about how to provide these targeted and intensive transition strategies.

1.2.6. Transition for Autistic Students

The Education and Employment References Committee Senate inquiry (The Senate, 2016) acknowledged that, "by failing to properly educate students with disability in their school years, Australia is setting up students for a lifetime of disadvantage, unemployment, low levels of mental and physical health and social isolation, along with ongoing welfare dependence" (p. 33).

The conceptual basis for the problem lies in the purpose of education and what is needed for schools to achieve these goals. The Alice Springs (Mparntwe) Declaration for Education in Australia (Education Council, 2019) states that the goals of an Australian education are:

1. The Australian education system promotes excellence and equity.
2. All young Australians will become – confident and creative individuals; successful lifelong learners; active and informed members of the community (Education Council, 2019, p. 4).

Given that individuals with autism experience significant differences in the areas of social communication, behaviour, learning, and sensory experiences, this 'one-size-fits-all' approach to post-school transitions does not provide these individuals with the skills, knowledge, attitudes, or support across the various domains needed to make this transition successful. The difficulty is that the characteristics of young people on the autism spectrum mean that they require additional or different knowledge, skills, and support to achieve these goals.

1.2.7. Effective Transition Practices

Effective transition practices during the school years have been shown to support a positive QoL for autistic individuals in the early adult years (Pillay et al., 2022). The Taxonomy for Transition Program (TTP) framework is an effective framework that can be used to supporting transition-focused education for students with disability (Kohler et al., 2016). While it has not been empirically tested for use with autistic students, it has been shown to be an effective approach for schools wanting to improve their transition-focused education. The framework consists of five categories: student-focused planning; student development; family involvement; program structure; and interagency collaboration (Kohler et al., 2016). Each category should be considered in planning transitions for students. Peter and Heron (1993) found that the use of the framework resulted in overall gains for students with autism as they moved from school to post-school options.

The TTP framework was developed in the United States and was implemented there as part of the legislative response to post-school outcomes for people with disabilities in the United States (Kohler & Field, 2003). The use of transition-focused educational practices, and in particular of the TTP framework, is not legislated in Australia (O'Neill et al., 2016). As a result, while the TTP framework has been verified as being appropriate and effective in the Australian and Queensland educational contexts (Beamish et al., 2012; O'Neill et al., 2016), its use is inconsistent and dependent on individual school choice. It is therefore appropriate to suggest that evidence-based transition practices are still under development across Queensland schools.

The views of young people on the autism spectrum who have transitioned from school to post-school options, and who are aware of the skills needed and the difficulties that they are facing in achieving positive QoL, are critical information for all key stakeholders: autistic individuals and their parents, teachers, employers, and the broader community. In particular, mainstream Queensland secondary schools wanting to improve their transition practices to support positive QoL for their autistic students can learn a great deal from listening to the voices of autistic individuals and their families.

1.3. The Research Questions

This study addressed the following overarching research question informed by three research sub-questions:

How do young autistic adults perceive the interaction between secondary school transition practices and post-school quality of life?

1. ***How do young autistic adults perceive their current quality of life?***
2. ***How and why have secondary school transition practices influenced the quality of life of young autistic adults?***
3. ***What are possible enablers of the implementation of effective transition practices in secondary schools?***

The first research question addresses the concept of QoL from the young autistic adults' perceptions. While research has consistently shown that young people with autism have poorer QoL across all domains (Shogren et al., 2015), more contemporary research has found that young autistic people view their QoL in a much more positive way (Halder & Bruyere, 2021). The differences in these outcomes seem to rely specifically on who is asked about the autistic individual's QoL. That is, when parents, teachers and other stakeholders are questioned about the young autistic person's QoL, the outcomes are consistently poor. By contrast, when the young people themselves are asked to rate their QoL, the outcomes tend to be more positive (Halder & Bruyere, 2021). It is important to acknowledge that QoL, when stated for another person, evokes a direct comparison with the expectations of the person giving the rating. Thus, QoL ratings for a young autistic adult will be provided based on the expectations of someone who does not experience autism and thus has very different expectations. For example, a young person's mother will rate her child's social engagement based on her beliefs about what would be good quality social engagement. This might mean that, from the mother's perspective, the young person needs to have at least five close friends and several acquaintances to achieve a good QoL in the social engagement domain. Young autistic people themselves, however, may not have the same value for social engagement. For them, one close friend may be all that they want, and so if they have one close friend their mother may rate their QoL as low, while they themselves will rate it as high. Given that this study aimed to share the perceptions of young autistic people, it was vital that they shared their perception of their own QoL.

Additionally, to discuss how secondary school transition practices have impacted on young autistic adults' QoL, it was critical for them firstly to identify and discuss how they perceive their current QoL within a domain, so they were then able to reflect upon why this was the case for them. If they perceived this domain to be positive, why was this the case? What were their own expectations in this domain, and how were they meeting these expectations?

It was from this stance that the young people could share their understandings of how and why secondary school transition practices had impacted on their own QoL. In answering the second research question, the young people discussed the skills, knowledge, and attitudes that had allowed them to meet their QoL expectations and they reflected on how their time at school helped them to develop these skills, knowledge, and attitudes. Alternatively, which skills, knowledge, and attitudes did they not have, and why did they believe that they did not learn those skills, knowledge, and attitudes in the secondary school context? Furthermore, the young people were able to articulate how the school had, or had not, assisted them in generalising these skills, knowledge, and attitudes from the secondary school context into post-school options.

Finally, it was expected that young autistic individuals would offer suggestions regarding possible enablers of the implementation of effective transition practices in Queensland secondary schools. That is, if skills or attitudes were taught well, what allowed this to happen in the secondary school context? Conversely, if skills or attitudes were not taught, or if these skills or attitudes were not generalised to post-school options, what would have enabled this to occur?

1.4. The Research Approach

This research was situated within an interpretivist approach and used a qualitative methodology to investigate the research problem. An interpretivist approach is based on the proposition that individuals interpret each experience of their lives and subsequently construct their own interpretation of reality (Ary et al., 2014; Johnson & Christensen, 2017). Through an interpretive lens, qualitative researchers seek to understand social reality from the individual's perspective within a specific context (Cohen et al., 2017). The purpose of the research study was to answer the ***what, how,*** and ***why*** questions (Merriam, 1998; Stake, 2005) of transition practices in secondary education and the impact that they had on the individual's post-school QoL.

Investigating these questions recognised that individuals have varied experiences and perspectives, and thus interpretations, of the transition practices put into place throughout secondary schooling, the transition from school to post-school, the QoL experienced in the post-school environment, and the relationships between transition practices and QoL. Thus, this study was designed to understand the reality of transition-focused education from the perspectives of young autistic adults, and their interpretations of the impact that these transition practices had on their current QoL. Importantly, this knowledge base was founded on the voice of autistic people, which have all too often not been included in past research (Milton, 2014), and aligns with the research expectations of autistic people and their families; that research should focus on QoL throughout the lifespan and on supporting positive outcomes for autistic individuals as they move out of childhood and adolescence into adulthood (Pellicano et al., 2014; Roche et al., 2021).

Through employing specific research methods and ensuring that the data collected and analysed are an accurate representation of the individual's lived experience, interpretivist research attempts to study social phenomena in a rigorous and systematic manner (Cohen et al., 2017). In line with the interpretivist approach, a multiple case study was used to elicit and analyse data. Bloomberg and Volpe (2019) described case study research as an "intensive description and analysis of a phenomenon, social unit or system" (p. 11). Through the use of multiple cases in the study, it was intended to provide an intensive description and analysis of each unique case, and subsequently to use these combined descriptions and analyses to help to understand the collective phenomenon of the cases by illuminating the themes that appeared within and across the cases (Merriam, 1998; Stake, 2005).

Data were collected from young autistic adults regarding their perceptions of the interaction between the transition practices used at the secondary school that they had attended and their current QoL as a young adult. The goal of using multiple case studies (Merriam, 1998; Stake, 2005) in this research was twofold. The first goal was to understand the unique perspective that individuals on the autism spectrum had about their transition to post-school options and the role of schooling in this transition. The second goal was to provide multiple data sources to help stakeholders to understand and interpret the interaction between the secondary schooling transition practices and the post-school QoL of young autistic adults.

Semi-structured interviews can be especially effective for accurately representing the individual participant's thoughts, feelings, and beliefs (Merriam, 1998; Stake, 2005) and were the primary data collection technique used throughout the research. These interviews were conducted with young autistic adults and their parent/s or carer/s. The semi-structured interview allowed the researcher to structure the interview questions to ensure that they addressed each research question adequately, while allowing specific beliefs or concerns of the students to be captured in a way that enhanced the study. The information sought in the research was the interaction between two already well-established frameworks – Kohler's (1996) Taxonomy for Transition Programming; and Schalock's (2004) Framework for Quality of Life (QoL) for people with intellectual and developmental disabilities. Hence the interview questions were developed and structured within the categories of these two frameworks. The aim of the interview questions was to guide the participants' discussion about the phenomenon within these categories, while also allowing areas of particular relevance and interest to be introduced by the participants themselves (Bloomberg & Volpe, 2019; Stake, 2005).

The data analysis process for this qualitative research study was thematic analysis through coding. Thematic analysis is a process that aims to bring order to, and to make sense of, the large number of data that were collected during semi-structured interviews (Miles et al., 2014). Given the study's research questions, and the focus on the participant's perceptions of the interaction between transition practices and post-school QoL, coding approaches designed to highlight participant voice and subjective experience within the aforementioned established frameworks of knowledge, Taxonomy for Transition Programming (Kohler & Field, 2003) and QoL (Schalock, 2004), were used in the first cycle coding of data. The perspectives provided by the young autistic adults and their parents were coded within the domains from the two frameworks. Second cycle coding then explored the themes within each of these domains for each participant, synthesising the perceptions and identifying the key themes within each domain. This process further condensed the data and developed more integrated patterns within those data (Miles et al., 2014).

In case studies with multiple cases, it is this second cycle of coding, or final level of thematic analysis, that provides the foundation for cross-case analysis (Miles et al., 2014; Saldana, 2016). Following data analysis of each individual case, a cross-case analysis was carried out with the goal of identifying those themes that cut across cases and that were used to deepen understanding and explanation of the phenomenon (Merriam, 1998; Miles et al., 2014). Thus, the similarities, differences and patterns in the perceptions of each young autistic adult offered a deeper understanding of how secondary school transition practices interacted with post-school QoL for those participants.

Credibility and trustworthiness of the research were supported through a number of strategies. There was a clear articulation across the conceptual framework, research questions, data collection, and data analysis to support the credibility of the research (Merriam, 1998; Stake, 2005). The use of multiple case studies allowed a deeper understanding of the phenomenon and supported the possibility of transferability to other contexts (Yin, 2014). Trustworthiness was established through member checking of all data collected. Lastly, a clear audit trail was provided to allow an open and transparent review of the research processes (Miles et al., 2014; Saldana, 2016).

1.5. The Researcher’s Personal Positioning and Language Use

Throughout this thesis, I write as a professional, teacher and researcher, and as the loving parent of and advocate for a young autistic adult. Within the complexity of these multiple roles, I choose to acknowledge my role as a strong ally of autistic people and to identify as part of the broader autism community (Fletcher-Watson et al., 2019). With this acknowledgement, I would also like to highlight that I am a nonautistic person and therefore I can never fully understand or be 100% sure of my interpretation of autistic voices (Leadbitter et al., 2021). While the journey through doctoral study is an individual one, I have endeavoured to do my utmost to share knowledge and understanding that both support and encourage autistic voices.

In this thesis, my intention has been to add to the voices of all of those who advocate and support a strengths-based approach to autism research (Niemiec et al., 2017). Throughout, I have acknowledged the strengths, interests, and contributions of autistic people, while recognising the difficulties that they face in navigating a society structured according to nonautistic knowledge and understanding (Leadbitter et al., 2021). I have also taken a strengths-based approach to working with the families of young autistic adults. I have acknowledged the key role that families play in the lives of those on the autism spectrum, and I have focused on what families do to encourage and support their young adult, as opposed to focusing on the outsiders' perceived cost of this encouragement and support. Additionally, I have used a strengths-based approach to considering the practices of schools in educating and supporting young people on the autism spectrum. Again, the focus has been on what schools can do to improve their educational and supportive strategies, as a strengths-based approach includes continual reflection on what is done and what can be done differently to maximise the encouragement and support of young people who experience disadvantage in educational contexts.

I acknowledge that "language use is constructive of social life; through language we make a case, take a particular stance, and produce identities" (Bottema-Beutel et al., 2020, p. 3). I concede that with language use there is "no neutral option independent of an ideological stance" (Bottema-Beutel et al., 2020, p. 4). As part of my strengths-based approach I chose to express my respect and consideration through the Australian autistic community's identified preference for language use (Bottema-Beutel et al., 2020). Throughout this thesis, the terms ***autistic***, ***autistic person,*** and ***person on the autism spectrum*** were used. Thus, taking the approach that autistic people should be directing the language used to describe them (Botha et al., 2020), the use of identity-first language was the primary choice made throughout this thesis with the inclusion of "person on the spectrum" as a person-first language choice that is considered least offensive by autistic people (Bury et al. 2020; Bottema-Beutel et al., 2020).

To refer to those who do not identify as autistic people I have used the term ***nonautistic***. This was in recognition that the community is made up of a diverse range of people, and that the characteristics experienced by both autistic and nonautistic people can be both similar and different across domains. Nonautistic people are those people who do not identify themselves as being autistic. This does not mean, however, that they do not or will not experience other forms of diversity throughout their lives (Bottema-Beutel et al., 2020).

The choices made with language use in this thesis were in response to ongoing discussion and debate, with the use of person-first language (person with autism) or identity-first language (autistic person) a primary point of disagreement. Kenny et al. (2015) found that, in general, people with close ties to the autism community, such as autistic people and parents of and advocates for autistic people, endorse the use of identity-first language, while most professionals who work with autistic people prefer the use of person-first language. As a person who exists in both worlds, my use of person-first and identity-first language emphasises my diversity of roles and represents the variety of views within the autistic community.

Person-first language is advocated by the American Psychological Association (APA) as the preferred language style to be used in academic writing and daily discourse about people with disability (Dunn & Andrews, 2015). It is based on the principle that individuals are persons first, with their disability being just one aspect of their identity. Person-first language was developed with the expectation that it would act as an equaliser, ensuring that all people would be referred to as a person-first before the use of any descriptive terms (Dunn & Andrews, 2015; Gernsbacher, 2017). Recent research conducted by Gernsbacher (2017) found that person-first language is more often used for persons with disabilities than for persons without disabilities; more often for children with disabilities than for adults with disabilities; and most often for people with disabilities that are seen as less desirable and more severe, with intellectual disability and autism being the disability categories most often referred to using person-first language (Gernsbacher, 2017). This would seem to indicate that person-first language, despite its noble intentions, may unintentionally further stigmatise those with disability, particularly those with disabilities such as autism.

Conversely, identity-first language, as used throughout this thesis, is founded on a strengths-based premise. It acknowledges the common principle that the placement of positive pronouns in front of a noun avoids the implication that a disability, specifically autism, is inherently negative (Kenny et al., 2015). It respects individuals' right to accept that autistic characteristics are an important part of themselves, and that the two, personal identity and autism, cannot be separated (Glasby, 2015). Moreover, it serves as a leveller, bringing the use of identity-first language more into line with that typically used for those people without a disability (Dunn & Andrews, 2015; Gernsbacher, 2017).

The use of both person-first and identity-first language to refer to people with and without disability throughout my research was intended to recognise the inherent intentions and challenges of both language styles (Dunn & Andrews, 2015; Gernsbacher, 2017), to challenge the thinking of all those who work with and write about autistic people (Dunn & Andrews, 2015; Gernsbacher, 2017) and to contribute to the open discussion about the impact of language use on people with autism. Finally, my intention was to promote a growing awareness and acceptance of positive emotions towards autism (Bottema-Beutel et al., 2020).

1.6. Overview of the Thesis

This doctoral thesis begins with **Chapter 1**, which has provided an overview of the context and significance of the research problem. It described the challenges associated with the transition of autistic adolescents from school to post-school options, the poor outcomes associated with this transition and the current transition-focused processes in place in Queensland secondary schools. The research questions and research approach were then discussed to show how this study was designed to address the question: ***How do young autistic adults perceive the interaction between secondary school practices and post-school quality of life***?

Chapter 2 provides an overview of the current literature regarding the key areas that led to the development of the research problem. Following the literature about the specific needs of autistic adolescents and the resulting poor outcomes of young autistic adults, through to the recommended versus actual practices used in current transition practices, the literature review identified the need for research to understand and share the voices of young autistic adults about the current transition practices and what impact they had on the participants' QoL.

In **Chapter 3,** the conceptual framework that underpins the research study is introduced. The overarching theory, self-determination theory (Deci & Ryan, 2002), is explained, followed by a discussion of autism, the social interactionist model of disability and the two frameworks identified earlier in this chapter: Taxonomy for Transition Programming (TTP) and Quality of Life (QoL). The strong links between these frameworks and self-determination theory are detailed to show how the researcher conceptualised the study.

Chapter 4 discusses the research paradigm and methodology. As is appropriate for a qualitative research study, the focus of this chapter is on providing rich descriptions about the processes followed throughout the study, from the beginning understanding of the researcher through to participant selection, data collection and data analysis, with an account of the ethical dimension of the research.

In **Chapter 5**, Research Question 1 is answered: ***How do young autistic adults perceive their current quality of life?*** Rich descriptions of the nine research participants, and of their family's perceptions, are shared. The QoL for these young autistic adults is considered through Schalock's (2004) Quality of Life framework, considering wellbeing, social participation, and independence.

Chapter 6 presents the cross-case analysis of the young autistic adults' perceptions of their current QoL. Both similarities and differences across cases will be considered, with both providing support for an overall perception of QoL by the young autistic adults and their families.

Chapter 7 explores Research Question 2: ***How and why have secondary school practices influenced the QoL of young autistic adults?*** In this chapter, the perceptions of the young adults and their families are shared in detail. This chapter is presented through the Taxonomy for Transition Programming Framework (Kohler et al., 2016) and how it links to the QoL from Chapter 5.

In **Chapter 8**, the cross-case analysis of the transition practices experienced and the impact on QoL are presented. This cross-case analysis provides clarification about the school-based environmental factors that influence post-school QoL for young autistic adults.

Chapter 9 brings together Chapters 5 and 6 to respond to Research Question 3: ***What are possible enablers of the implementation of effective transition practices in secondary schools?*** This chapter combines the data analysis from Chapter 5 about QoL and Chapter 6 about transition practices and their impacts to identify key enablers for schools, parents, and young adults.

The final chapter in this thesis, **Chapter 10**, shares the outcomes of the research and possible ways in which this information can be used across several domains – theoretical, conceptual, methodological, empirical, policy and practice, to support effective school to post-school transitions for young autistic adults.

1.7. Chapter Summary

This chapter introduced the context and the significance of the research problem. Firstly, the challenges faced by young autistic adults as they transition from school to post-school options were established, including the poor post-school outcomes that are often experienced. This was considered in the context of the current transition practices that are used in Queensland secondary schools, what transition practices are used and how these practices are tailored to the specific needs of autistic students.

In the second half of the chapter, the three research questions were introduced. These research questions allowed the researcher to investigate the overall research question: ***How do young autistic adults perceive the interaction between secondary school transition practices and post-school quality of life***? The research approach was also introduced, outlining the data collection and data analysis strategies that were employed to address the research questions. Finally, the researcher shared her own personal positioning in conducting the research, including the personal use of terms relating to autistic people and the reasons for this form of language use.

CHAPTER 2: SITUATING THE STUDY

2.1. Chapter Overview

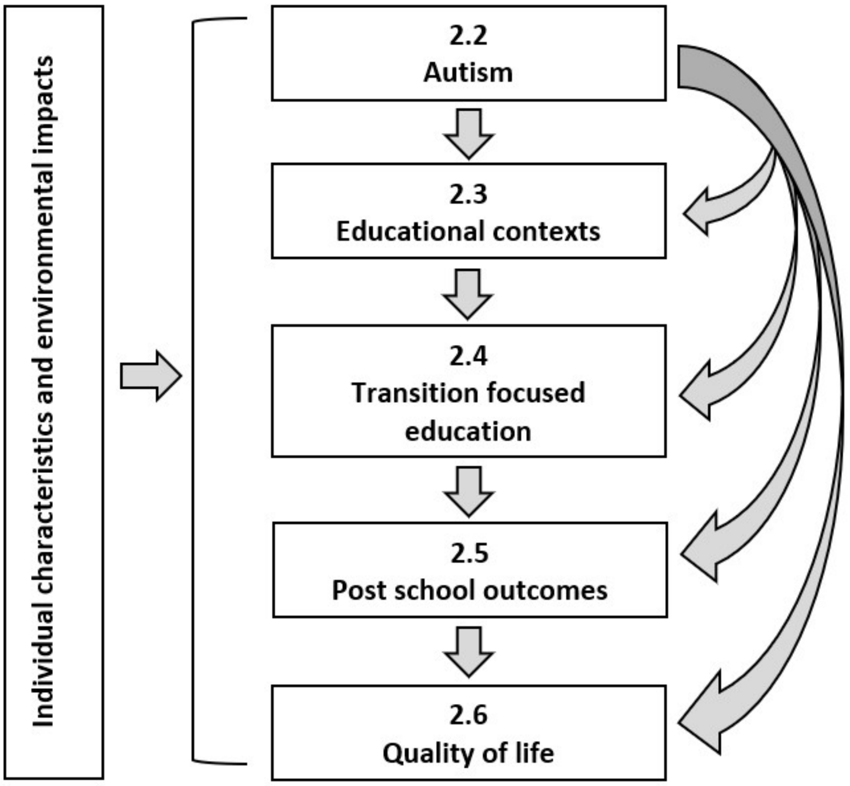
Autism is a lifelong neurobiological disorder that has significant impact on individuals and their ability to interact and function across their lifespan. In particular, autistic individuals' experience in the context of school and as they transition from school to post-school options is one that poses many difficulties for individuals, their family, the community, and broader social contexts. The following literature review considers the autistic individual's experience prior to, during, and after this transition from school to post-school options. Importantly, the literature review shows the significant changes that have occurred in the research conducted on the autistic experience, which has moved from looking only at the individual impairments experienced by individuals on the autism spectrum to a recognition of the significant impact that environments play in their experience. The complexity and interrelatedness of individual characteristics, and environmental factors, is considered in relation to the experience and outcomes of transition from school to post-school options.

A schematic diagram (see Figure 2.1) has been presented to help to structure the literature review, showing that the first consideration is that of the autistic experience. The diagram highlights what autism is, how it impacts the individual and the environment, and how and why the conceptualisation of autism has changed over time. The impact of the autistic experience is then considered in relation to secondary school, including the outcomes that autistic students typically experience during this critical phase of schooling across the various domains – academic, social, and emotional. Throughout the discussion of schooling, the various individual autistic characteristics, and their impact are considered. However, the environment of educational contexts along with the roles and responsibilities of educational contexts is also addressed with a specific focus on how the school environment impacts on schooling outcomes for students on the autism spectrum. In the context of schooling, specific attention on transition-focused education is emphasised.

Transition-focused education is those educational practices and supports implemented to assist young people as they transition from school to post-school options and has been shown to be critical to the post-school success of young people who experience disability (Kohler & Field, 2003). The role of schools in preparing all young people for life as an adult, and how this is working for young people on the autism spectrum are the focus of this section. It also suggests that the current educational context does not incorporate effective transition-focused education into secondary school practices and that this, in turn, is not supporting positive post-school outcomes for many autistic individuals. Specifically, outcomes in terms of employment, post-school education, independent living, and social participation are explored under the lens of the autistic experience. Finally, how these outcomes impact on young autistic adults' QoL is discussed. The purpose of this literature review, in considering each of these different sections, is not to show each as separate from the others, but rather to show their interconnectedness in ensuring that young people on the autism spectrum can live fulfilling, productive, and responsible adult lives.

Figure 2.1

Schematic Diagram of Literature Review



2.2. Autism

Autism is a relatively new diagnosis that has seen rapid changes over the years in terms of diagnostic criteria, characteristics, and prevalence rates. Originally described by Kanner in the 1940's, autism was labelled as a childhood form of schizophrenia (Cook & Willmerdinger, 2015). At this early stage of research, autism was thought to be caused by emotional or psychological factors and was listed as a rare disorder. In the late 1990s and early 2000s, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994) used the term ***pervasive developmental disorders*** to describe a range of conditions, including, ***autism, autistic disorder, Aspergers syndrome*** *and* ***pervasive developmental disorder not otherwise specified (PDD-NOS)***. These disorders were labelled as different conditions under the umbrella term of autistic disorder; however, all related to the three core impairments – impairment in social interaction; impairment in communication; and restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities, and were recognised as lifelong neurobiological conditions. During this time, the prevalence rates of diagnosis increased rapidly from an estimated 4.5 diagnoses per 10,000 children to an estimated prevalence rate of one child in every 110 by 2009 (Cook & Willmerdinger, 2015).

In 2013 the DSM-5 (American Psychiatric Association, 2013) was released with substantial changes to the labelling and diagnostic criteria for autism. All previous disorders listed in the DSM-IV (American Psychiatric Association, 1994) were now subsumed under the label ***autism spectrum disorder (ASD)***, and the core impairment areas were reduced from three to two with the previous domains of social impairments and communication impairments being collapsed into one domain of social communication impairments. Thus, the core impairments of autism, according to the DSM-5 (American Psychiatric Association, 2013), are social communication impairments and restricted and/or repetitive behaviours, interests, or activities. The social communication impairments characteristic of autistic people includes difficulties such as social-emotional reciprocity, nonverbal communicative behaviours, and developing, maintaining, and understanding relationships. The restricted, repetitive patterns of behaviour may include repetitive motor movements, an insistence on sameness, an inflexible adherence to routines, ritualised patterns of verbal or nonverbal behaviour, highly restricted, fixated interests, and hyper or hyposensitivity to sensory input (American Psychiatric Association, 2013). Associated features of autism spectrum disorder may include a wide gap between intellectual and adaptive functional skills, motor deficits, self-injury and challenging behaviours, and high rates of co-occurrence of an intellectual disability and mental health challenges such as anxiety and depression (American Psychiatric Association, 2013).

Additional changes included the introduction of disorder severity coding, with level 1 requiring the highest level of support and level 3 requiring the lowest level of support, and changes to the number of symptoms required for diagnosis (Sturmey & Dalfern, 2014). These changes were controversial for many people with the diagnosis and their families, particularly for people who had a previous diagnosis of Aspergers syndrome. While some people were not concerned with this change and felt that the term ***spectrum*** was more representative of the variety of autistic experience, others had created a strong community identification around Aspergers and did not want to be included under the label of ASD (Nelson, 2020).

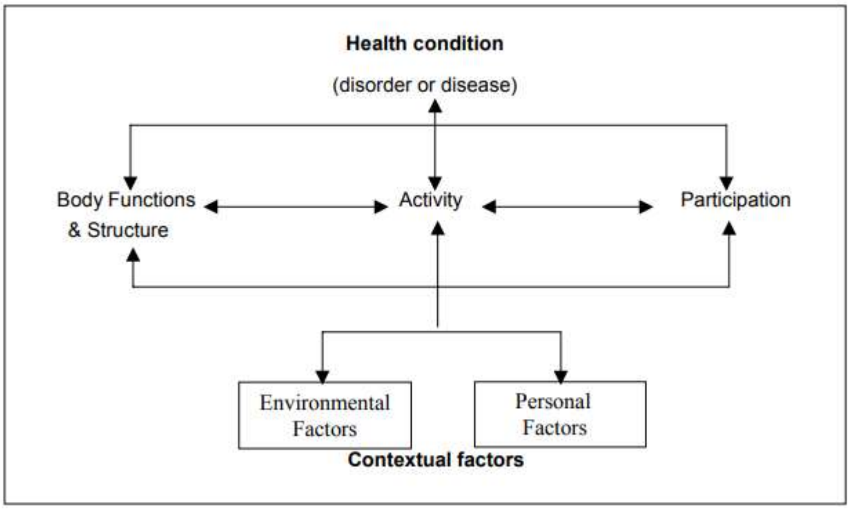
While there were concerns that this change in diagnostic criteria would result in fewer people receiving a diagnosis (Sturmey & Dalfern, 2014), this has not been the case. Across the world, autism prevalence rates continue to rise, with Australian statistics indicating a 25.1% increase in the number of Australians reported to have a diagnosis of autism from 2015 to 2018 (Australian Bureau of Statistics [ABS], 2019). Autism Spectrum Australia (n.d.) estimated that one in 70 Australians are on the autism spectrum, although it is important to acknowledge that actual prevalence rates are difficult to determine and vary significantly depending on the criteria used (Chiarotti & Venerosi, 2020). Despite the difficulty in establishing exact prevalence rates, a continued increase is widely recognised and suggested to have occurred owing to a variety of reasons, including better recognition and diagnosis of the disorder, changes to the DSM diagnostic criteria, differences in study methodology, or a genuine increase in the frequency of ASD (American Psychiatric Association, 2013). It has also been suggested by May et al. (2020) that the introduction of policies, including educational and community funding and support specific to autism, may have also contributed to the increase in official diagnoses.

While the preceding descriptions of autism are important as they relate to the recognition and diagnosis of ASD, it must be acknowledged that they refer specifically to autism using the medical model of disability. This can be seen through the use of medical terms such as ***disorder, impairment, prognosis,*** and ***treatment*** throughout the manual (American Psychiatric Association, 2013). Alongside the changes within the DSM-5, however, community and individual understanding of autism has also changed and developed over the years. This has primarily been the result of changing the focus of understanding from the medical model of disability, whereby autism is seen as a disorder that results in negative outcomes and that needs to be fixed, to more contemporary models of disability. Following debates around critical theory, the social model of disability gained popularity (Graham et al., 2020). In this model, disability is not attributed to the individual; rather disability is seen as a socially constructed problem (Graham et al., 2020). Thus, within this understanding, addressing disability demands a social and political response (International Classification of Functioning Disability and Health [ICF], 2002). The International Classification of Functioning, Disability and Health [ICF] (2002) stated that, although both models are partially valid, neither model on its own adequately addresses the complex phenomenon of disability. Thus, a model that attempts to take key aspects from both models and combines them to recognise both individual and environmental factors is the biopsychosocial model of disability.

Within the biopsychosocial model of disability, “disability and functioning are viewed as outcomes of interactions between health conditions and contextual factors” (International Classification of Functioning Disability and Health [ICF], 2002, p. 10). According to this view of disability, disability does not exist within the person but results from an interaction between the characteristics of the individual, including personal factors, impairments, or differences, and environmental factors such as social attitudes, social characteristics, and social structures. Figure 2.2 shows a diagrammatic representation of the biopsychosocial model of disability. This model indicates the complex interplay that both personal and environmental factors have in the outcomes related to a disorder or difference such as autism. Thus, the experiences of and outcomes for autistic individuals are not a direct result of ***autism*** but are the result of the impact that autism has for individuals on their body functions and structure, the activities provided to them, and the level and type of their participation related to these activities.

Figure 2.2

Representation of the Biopsychosocial Model of Disability (International Classification of Functioning Disability and Health [ICF], 2002)



A newer model of disability is the human rights model (Graham et al., 2020), where human dignity is central to decision making regarding the person with disability. From this perspective, impairment must not hinder the human rights of any person, and the United Nations Convention on the Rights for People with Disability [UNCRPD] (2006) must take precedence over all other factors in decision making. While the different models of disability all have their strengths and weaknesses, each model can be seen to be most useful in specific contexts (Graham et al., 2020). When requiring diagnosis, the medical model is most useful; when fighting for legislative and policy change, the social model is most useful; and, when implementing the UNCRPD, the human rights model is most useful. In the context of education, the biopsychosocial model is appropriate as it recognises the effects of individual differences alongside the provision of supportive environments in achieving positive educational outcomes.

Regardless of the model of disability used in a specific context, the discussion about each of these models has had a significant impact on the understanding of and advocacy for people who experience disability, including people on the autism spectrum. In turn, this has resulted in a different conceptualisation of autism from a disorder to a natural form of human diversity (Bottema-Beutel et al., 2020). This different conceptualisation has also changed the definition of autism used by many autistic people and their advocates. ASPECT (n.d.) defined autism as a "condition that affects how a person thinks, feels, interacts with others, and experiences their environment", and emphasised that every person on the autism spectrum will experience autism differently, and that from ASPECT's perspective autism is "a different brilliant". This move away from the medical definition and understanding of autism allows the use of more positive language and a strengths-based focus relating to autism (Niemiec et al., 2017).

These alternative definitions have also allowed a move away from the linear views that have permeated the understanding of autism. Within this linear view, autism is seen as existing along a continuum, from most severe to least severe. As described by many autistic authors and advocates, this is a misrepresentation of the experience of autism (Leadbitter et al., 2021), with each autistic individual experiencing different strengths and needs within each characteristic – social, communication, behaviour, sensory, motor skills, executive functioning, and adaptive skills. Therefore, newer conceptualisations of the spectrum of autism refer instead to a kaleidoscope or constellation of autistic characteristics, thus recognising that every autistic individual experiences each aspect of autism differently. The constellation of autism characteristics provides a representation of autism as experienced across multiple domains; intellectual functioning, communication, social, physical, sensory, and strengths and interests, and that each person on the autism spectrum has different experiences within each domain. It is this constellation of different experiences across multiple domains, combined with the variety of environmental factors present for individuals, that results in the significant heterogeneous presentation of autism.

This constellation of autistic characteristics is beneficial in recognising and describing the functional outcomes of autistic individuals, and the environmental adaptations and supports needed to foster more positive outcomes. As would be expected with such a wide variety of characteristics, the impact that these have on the individual's level of functioning and QoL is also highly variable (Aubineau & Blicharska, 2020). Interestingly, while this variability of outcomes is recognised, most research, such as the meta-analysis conducted by van Heijst and Geurts (2015), suggests that people on the autism spectrum experience much poorer QoL than people not on the autism spectrum. Furthermore, this empirical study showed that age, IQ, and symptom severity did not necessarily have a direct impact on overall outcomes or QoL. This means that the majority of people on the autism spectrum experience poorer outcomes than nonautistic people across life domains, from early childhood through to adulthood, regardless of the severity of autism or whether or not they have a co-occurring intellectual disability or a mental health condition.

It is important to consider, however, that poorer outcomes and variability in outcomes may also be a reflection of the "person-environment fit, or balance between objective (i.e. societal demands, expectations, accommodations) and subjective (i.e. individuals' needs and preferences) outcomes" (Oakley et al., 2021, p. 390). This idea is supported by the findings from Mattys et al. (2018) that searching for balance between the societal expectations placed on individuals on the autism spectrum, and what was possible owing to their individual characteristics, was a key theme identified by young autistic adults as they transitioned from school to post-school options. It is also supportive of the biopsychosocial model of disability that suggests that both individual factors and environment must be considered when researching outcomes for autistic individuals.

Given that most research to date has been conducted based on the medical model of disability and given the assumption that the key factor in outcomes relates to individual characteristics, there is a need for researchers to consider the interconnection between individual characteristics and the environments in which the individual grows and develops (Pellicano et al., 2014). Thus, in investigating young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school QoL, equal attention must be paid to the educational environments in which children and adolescents on the autism spectrum develop and learn.

2.3. Education

Education in Australia is considered a basic right for all young people and is underpinned by two goals. The first is to ensure that "the Australian education system promotes excellence and equity”, and the second is that “All young Australians become confident and creative individuals, successful lifelong learners, and active and informed members of the community” (Education Council, 2019, p. 4). Thus, the goal of education in Australia is to prepare all young Australians for their future adult roles in the Australian community. It is recognised that, within a shared community responsibility, schools play a vital role in shaping the development of young people and have an obligation to provide young people with the skills, knowledge, and attitudes that they need to function as adults in our society.

While primary school in Australia is considered the stage for developing foundational skills, the role of secondary schools is seen to be much more. Not only are secondary schools to continue to develop the academic, social, and emotional skills of students, but they are also expected to help students to plan and prepare for their future as adults (Mazzotti et al., 2014). This goal, helping to prepare students for adult life, is strongly supported throughout the literature (Mazzotti et al., 2013; Mazzotti et al., 2014), and is further enhanced in international and Australian educational policy where secondary schooling is seen as the avenue through which all students will be prepared for further education, employment, and independent living (Cumming et al., 2020; Education Council, 2019; O'Neill et al., 2016). Specifically, the Alice Springs (Mparntwe) Education Declaration (Education Council, 2019) indicated that secondary schooling should provide all students with the high quality education necessary to complete their secondary schooling, make a smooth initial transition to further education, training, or employment, and acquire the cognitive and social skills necessary to reach their full potential after school. In fact, Kucharczyk et al. (2015) suggested that the “outcomes achieved in the early years after graduating from secondary school serve as a leading measure of the effectiveness of the educational services and supports provided during secondary school” (p. 329).

Furthermore, with the focus on inclusive education (Graham et al., 2020; Hyde et al., 2021), the Disability Discrimination Act [DDA] (Australian Government, 1992), the Disability Standards for Education [DSE] (Australian Government, 2020), and the inclusive education policy (Queensland Government, 2021b) supporting the enrolment of students with disabilities in mainstream schools, there is an increasing expectation that autistic adolescents will attend regular secondary schooling during these vital years of adolescent development. Although there is no one, widely accepted definition of inclusion, inclusive education in Australia is generally recognised as all students attending regular schools, having their academic, social, and emotional needs met, and being accepted and respected members of the school community (Boyle & Anderson, 2020; Hyde et al., 2021). Therefore, the expectation is that students on the autism spectrum will be able to attend their local secondary school, complete their secondary school education, make a smooth transition to further education, training, or employment, and acquire the cognitive and social skills necessary to reach their full potential after school (Education Council, 2019).

While these are relevant and valuable goals, the increasing diversity of the young people accessing our schools is challenging the education system's ability to achieve this for all individuals, including individuals on the autism spectrum. Recent reports conducted into Australian education indicated that not only is Australia failing to meet these goals for many of its disadvantaged students, but also the gap between those who do meet these goals and those who do not is increasing (Bonnor et al., 2021; Teather & Hillman, 2017). The Education and Employment References Committee (The Senate, 2016) found that there are substantial barriers for students who experience disability in attending and succeeding in Australian mainstream schools, and that this is resulting in significant costs incurred by individual students, their families, and the broader community. Within this Australian report, it was stated that there is an "ongoing and pervasive stigmatisation of students with autism and their families" (The Senate, 2016, p. 19) within mainstream schools, and that inclusive education is shown to have mixed results in both academic and social outcomes for autistic students (Waddington & Reed, 2017). This is concerning given that a report conducted by Autism Spectrum Australia [ASPECT] (2013) showed that, in 2012, 76% of adults who participated in the research had attended a mainstream secondary school. Although this was described as a time limited snapshot, inclusion is becoming more of a focus; thus, it is expected that these percentages are continuing to increase. The reality is that autistic students face various obstacles that may prevent them from making the most of their education

(Humphrey & Lewis, 2008), and that most young people on the autism spectrum experience poor outcomes in school across academic, social, and emotional aspects.

Inclusion in mainstream schools does not necessarily lead to students being more academically successful, with the academic achievement of many autistic students being lower than would be expected based on their IQ (Waddington & Reed, 2017). A comprehensive literature review conducted by Keen et al. (2016) demonstrated that, while there is a recognised correlation between IQ and academic outcomes achievement, many students on the autism spectrum function significantly below the level predicted by their IQ across a range of academic domains (Keen et al., 2016). This study also indicated that students on the autism spectrum show significant variability in academic achievement, and usually present an uneven pattern of achievement across different academic skill areas, for example, high achievement in mathematics while experiencing poor outcomes in writing and reading comprehension. Moreover, the gap between autistic and nonautistic students' academic achievement tends to widen as they move into adolescence, despite the emphasis placed on academic achievement in secondary school (Keen et al., 2016).

Current knowledge suggests that this can be attributed to autistic learners showing significant differences in how they process information. There is a general propensity whereby autistic learners process auditory or linguistic information at a slower rate, have difficulties processing multiple sensory pathways simultaneously, and show a tendency towards processing details rather than taking a global perspective (Fluery et al., 2014; Reinvall et al., 2013). At the same time, autistic learners may also show differences in executive functioning or self-regulation and metacognition, which includes skills such as planning, sequencing, problem-solving, self-initiation, and self-evaluation of tasks (Fluery et al., 2014; Hume et al., 2014). Rosenthal et al. (2013) conducted a study and found that, for autistic students, executive functioning abilities may decrease during adolescence, and that these differences have a significant impact on academic functioning in the secondary school context. It has also been suggested that autistic learners may have differences in their memory profile, with autistic people experiencing challenges with recalling words, sentences, and stories as well as everyday details such as people's faces, names, locations, and planned activities (Fluery et al., 2014; Reinvall et al., 2013).

Furthermore, this delayed recall appears to result in memory deficits (Reinvall et al., 2013).

More recent research, however, indicated that academic outcomes are also strongly influenced by the social experience of the young person in the educational context (Aubineau & Blicharska, 2020; Garcia & Hahs-Vaughn, 2021; Waddington & Reed, 2017). Some evidence suggests that, when young people on the autism spectrum experience limited social participation in school, they experience not only poor social outcomes, but also poor academic, emotional, and behavioural outcomes (Aubineau & Blicharska, 2020), although this study reflected the perceptions of the parents rather than the young people themselves and included a small number of participants. This is despite the assumption by many that the social communication difficulties experienced by autistic individuals mean that they prefer to be on their own and do not want to participate socially. These ideas, while very common among those who work with autistic individuals, are no longer accepted as accurate. Contemporary evidence indicates that people on the autism spectrum desire friendships and social inclusion in the same way that nonautistic people and people with other disabilities do (Mattys et al., 2018; Pellicano et al., 2019). Furthermore, social exclusion has significant impacts on all areas of functioning and development, especially in the key developmental period of adolescence where young people are forming their social identity (Arnett, 2014).

Autistic students were found to face more social challenges in secondary schools than in primary schools. In a literature review of studies relating to the social inclusion of autistic students, Mamas et al. (2021) found that inclusive education can both enhance and/or hinder social participation. Interestingly, of the studies that showed that inclusion enhanced social participation, the majority were conducted in primary school settings. Of the studies that showed the negative social participation effects of inclusion, the majority were conducted in secondary school settings (Mamas et al., 2021). The findings further indicated that adolescents in secondary school experience significantly more loneliness and have poorer friendship quality and a poorer social network. This supported research conducted by Humphrey and Symes (2011), who found that autistic adolescents in secondary schools spend more time on their own and less time in cooperative interaction with their peers. It also supported research that indicated that students on the autism spectrum experience increased negative interactions with their peers during adolescence (Sasson et al., 2017). Furthermore, findings from the McKinlay et al. (2022) study indicated that parents felt that their autistic children struggled socially at school, and that this had significant impacts on their child's wellbeing, particularly their emotional wellbeing and mental health. This is concerning given that the opportunity to interact with nonautistic peers is often cited as one of the key benefits of students on the autism spectrum attending mainstream schools (Humphrey & Symes, 2011).

Peer victimisation, including bullying and social exclusion, is another aspect of social participation in secondary schools that has been shown to have serious negative effects on educational outcomes, including enjoyment of school, feeling safe or unsafe at school, and demonstrating some measures of academic achievement (Adams et al., 2016). In the nonautistic population, peer victimisation has been shown to predict academic underachievement, school disengagement, and dropping out of school (McDougall & Vaillancourt, 2015). Adams et al. (2016) found that youth on the autism spectrum have very high rates of peer victimisation, and hypothesised that this leads to emotional distress that, in turn, leads to negative school adjustment for autistic students. This was supported in the Australian educational context, with respondents in the ASPECT (2013) survey rating the worst experience of their educational experience as social experiences, including experiences of bullying, and feeling lonely and isolated or 'out of place'. Furthermore, the Autism Spectrum Australia (2013) study highlighted that it was students without a co-occurring intellectual disability and attending mainstream schools who were more likely to have been bullied at school than those with an intellectual disability.

Thus, as a core characteristic of autism, social communication difficulties are recognised as a particularly problematic aspect of adolescence, and one that has significant impacts on the success of the individual across all areas of development within school contexts (Carter et al., 2014; Mazzotti et al., 2014). Social communication skills are recognised as the primary avenue through which all youth learn academic, social, behavioural, functional, and independence skills (Carter et al., 2014; Santrock, 2014). For autistic youth, the gap between existing social communication skills and increasing social expectations results in deficits becoming more pronounced throughout adolescence and secondary schooling (Hendricks & Wehman, 2009).

Another key characteristic of autism, sensory differences, has also been linked to the difficulties experienced in educational contexts. Results from Butera et al. (2020) indicated that sensory impact has a strong impact on school performance. It was shown that students in the classroom experience constant exposure to complex auditory and visual stimuli, and that they are required to integrate this sensory information in order to learn (Butera et al., 2020). As young people on the autism spectrum often experience difficulties managing this sensory overstimulation, it can result in poor sensory modulation, sensory distress, and limited engagement, which ultimately results in limited opportunities to process information and learn (Butera et al., 2020). Additionally, adolescents on the autism spectrum are shown to experience challenges in processing verbal and visual information simultaneously and in reorienting attention from one stimulus to another (Fluery et al., 2014), these are key characteristics required in secondary school settings. These factors have significant impacts on academic learning and social functioning and increase levels of anxiety. Costley et al. (2021) proposed that the school environment is one that results in high levels of anxiety for students on the autism spectrum.

While there is significant evidence to suggest that these individual characteristics impact on autistic adolescents functioning in the secondary school environment, it must also be acknowledged that the school environment becomes much more complex in secondary school. Aubineau and Blicharska (2020) suggested that some of the many complexities in secondary schools include moving between classrooms and different teachers, large numbers of students, increased free time, increased expectations with regard to individual organisation and planning, and noisier and less predictable environments. Yet in this period of transition, when autistic adolescents require the highest levels of support for continued development, the schooling context is one where there is a considerable reduction in the level of support and in the explicit teaching of these skills (Hume et al., 2014). It is not surprising then to find that both teachers and students indicate a significant mismatch between the characteristics of autistic students and the environmental contexts of secondary school education (Humphrey & Lewis, 2008). Rodden et al. (2019) went a step further to state that poor educational outcomes for students on the autism spectrum at secondary level are partially attributed to the fact that “they are required to fit into a system that is not designed to meet their needs” (p. 248).

The proposition then is that the individual characteristics of autistic adolescents are not solely responsible for educational outcomes; educational environments also play a significant role. A range of studies has shown this to be the case with social participation. Research by Brock et al. (2018) found large and statistically significant increases in peer interactions and appropriate play after the presentation of peer-mediated pivotal response training in the school context, while Aubineau and Blicharska (2020) found that one of the key enablers of positive outcomes in autistic adolescents in mainstream schools was having a friend at school. Finally, the systematic literature review by Mamas et al. (2021) regarding the social skills participation of autistic students highlighted that the social participation of students on the autism spectrum can be significantly influenced by pedagogical practices and climate as opposed to being the sole outcome of the individual student’s characteristics.

In the Australian context, while participants rated social experiences as the worst experience of their education, 80% also indicated that they had not received adequate support in this area (Autism Spectrum Australia [ASPECT], 2013). This study linked the experience of bullying with the adequacy of school social and behavioural support (Autism Spectrum Australia [ASPECT], 2013). Furthermore, it was shown that those respondents who cited bullying as the worst thing about the educational experience had a high level of ongoing support needs in adult life and were the least happy with their later social life. This supports the hypothesis that “individuals with ASD, who face exclusion and victimisation during their education years, are consequently debilitated in their confidence or capacity to navigate social interactions in adult life” (Autism Spectrum Australia [ASPECT], 2013, p. 28), and it is further suggested that this outcome is strongly mediated by school practices and culture.

Teacher characteristics such as a teacher’s skills, knowledge, and attitudes are also shown to be particularly important for both the academic and the social success of autistic students in mainstream schools (Costley et al., 2021; Humphrey & Symes, 2011; Rodden et al., 2019). Given the importance of both academic and social skills in future employment, independent living, and forming and maintaining relationships, it can be surmised that secondary school teachers' practices play a critical role in achieving the educational goals of autistic adolescents attending mainstream schools. However, research showed that secondary school classroom teachers were identified as having the most cautious attitudes towards the perceived benefits of inclusive education (Avramidis & Norwich, 2002), and most teachers do not perceive themselves as having the necessary training and support to provide adequately for autistic students' academic or social needs (Garrard et al., 2019; Humphrey & Symes, 2011). This was found by Rodden et al. (2019) to be because secondary teachers see their main role as being to teach subject matter and to enhance learners' academic potential. Thus, while secondary school teachers were aware of the academic difficulties experienced by autistic students, they saw this as being a result of individual characteristics rather than of their teaching practices. Similarly, while recognising the social difficulties experienced by students on the autism spectrum, some teachers did not see social inclusion as being part of their role, nor was the connection made between social exclusion and academic outcomes, as discussed previously. The study showed that teachers felt that it was the student's role to 'fit in' with the secondary school system, and that it was neither feasible nor preferrable to change the system to adapt to individual student needs (Rodden et al., 2019).

Yet ASPECT (2013) reported that teacher interactions and support systems were rated in the top three of the best things about autistic students' educational experiences. Conversely, teacher interactions and support systems were also rated in the top three for the worst things about autistic students' educational experiences. This finding highlighted the importance of the student-teacher relationship in educational contexts. Furthermore, it indicated that the experience of the individual student, positive or negative, relies heavily on individual teachers and on their level of knowledge, understanding, and acceptance of autism (Humphrey & Symes, 2011). Positive relationships between staff and students, based on a strong understanding of autism, greatly reduced the level of anxiety experienced, and supported the student's development of independent skills and coping strategies (Costley et al., 2021). By contrast, negative relationships and other people's general lack of awareness and understanding led to reduced acceptance and poorer academic, social, emotional, and behavioural outcomes for autistic secondary students.

Importantly, a number of these studies highlighted the impact of school experiences on outcomes and QoL in adulthood (Autism Spectrum Australia, 2012; Keen et al., 2016), and this links back to the role of education in preparing all young Australians for their future role in the Australian community (Education Council, 2019). While research is beginning to show that ongoing support at school age is a better indicator of outcomes and anticipated long-term prognosis than individual characteristics (Clark et al., 2018), the practices employed in most secondary schools appear to be facilitating poorer post-school outcomes for most young autistic adults. With autistic people having poor post-school outcomes in all areas of functioning (Bishop-Fitzpatrick et al., 2016; van Heijst & Geurts, 2015), it becomes evident that, while the educational goals for autistic adolescents may be the same as for all other students (Education Council, 2019), there is a need to ensure that secondary school programs address a range of specific needs across all developmental areas in order to meet these goals (Kucharczyk et al., 2015).

2.4. Transition Practices in Schools

Rue and Knox (2013) suggested that an effective way to address the specific group and individual needs of autistic adolescents in secondary schools and to improve post-school outcomes is through a comprehensive transition program. A transition program is defined by Rowe et al. (2015) as a program that "prepares students to move from secondary settings to adult life, utilizing comprehensive transition planning and education that creates individualized opportunities, services, and supports to help students to achieve their post-school goals in education/training, employment, and independent living" (p. 123). Research conducted a, a transition program can be used as the avenue through which appropriate educational goals and instructional strategies are chosen for an autistic adolescent's secondary education, and transition to post school options is supported (Winn & Hay, 2009).

Adolescence typically begins around the age of 13 and, in Australia, coincides with school students moving from primary school into secondary school. It is a particularly important time of development for any individual (Santrock, 2014), with adolescents encountering a period of significant change in their physical, social, and emotional development, as well as change in the social contexts and level of expectation placed upon them (Carter et al., 2014; Santrock, 2014; Smith & Anderson, 2014). This change also coincides with a change in the focus of education from solely foundational skills to foundational skills plus the skills needed for adult life (Santrock, 2014). For autistic adolescents, the changes that typically occur during this period are compounded by the individual characteristics of autism; social communication differences, differences in behaviours and interests, sensory sensitivities, and differences in executive functioning (Hendricks & Wehman, 2009; Hume et al., 2014; Humphrey & Lewis, 2008; Rue & Knox, 2013). They are further compounded by the changes in environmental expectations, goals, and support provided at this stage of education (Mazzotti et al., 2014).

Currently in Australian secondary schools, transition programs are implemented as a specific program that is ‘tacked on’ to the regular curriculum in the final years of secondary school, or the Senior Phase of Learning (Westbrook et al., 2015; Winn & Hay, 2009). The Senior Education and Training (SET) plan is to be completed in Year 10 and is written by schools to help to plan for the young person’s education and future career, to set goals, and to work towards those goals, and therefore it is an important part of the process for students’ transition to post-school life (Queensland Government, 2021c). In current educational practice in Queensland, however, the SET plan does not become a primary aspect of the young person’s education until the last few years of schooling, and thus it is implemented as an ‘add on’ to the educational program for the student. Given that research supports the need to start the transition process as early as possible (add reference), a key benefit of transition planning is currently not being utilised to support school and post-school achievement for Australian students on the autism spectrum.

The use of the term ***transition program*** may indicate that this would be an entirely separate program that could either be added on to a current program or operate independently. However, the term ***transition-focused education*** as suggested by Kohler (1996) implies that transition should be the primary focus guiding secondary school education. Research conducted by Kohler and colleagues that included reviewing research literature, conducting evaluation studies, and modelling transition project outcomes led to the development of the Taxonomy for

Transition Programming Framework (TTP) (Kohler & Field, 2003). The framework was later updated and expanded to ensure that it still fitted within the expectations of current educational best practice. The TTP 2.0 (Kohler et al., 2016) was developed and, while it retained the same overarching categories, additional information was added relating to how these categories could best be implemented in the school context.

The TTP framework is a "comprehensive, conceptual organisation of practices through which transition-focused education and services are developed and delivered" (Kohler & Field, 2003, p. 176), and identifies five categories: student-focused planning; student development; family involvement; program structures; and interagency collaboration. Within each of these categories, evidence-based practices have been researched and applied to ensure the effective outcomes of transition-focused education for adolescents with disabilities (Mazzotti et al., 2014; Rowe et al., 2015). While the taxonomy and its associated categories were not specifically designed and researched with autistic adolescents in mind, it was suggested by Wehman et al. (2014) that they characterise the best measure of current practice in relation to transition-focused education for adolescents with disabilities, including those with autism. The TTP has been used to identify and discuss evidence-based practices that research suggests are appropriate for transition-focused education for autistic adolescents, and several researchers have listed the evidence-based practices identified as fitting under the categories of the TTP (Mazzotti et al., 2013; Mazzotti et al., 2014; Mustian et al., 2012). For the purposes of this thesis, secondary school transition practices will be considered within the categories of the TTP framework. As such, a discussion of the TTP framework categories and how they apply to the secondary school transition practices for autistic adolescents will be considered.

The first category within the framework is that of student-focused planning. It includes the development of individual student goals, student participation in planning and decision making, and students' self-evaluation of progress towards goal achievement (Kohler et al., 2016). This clearly places the individual student at the centre of the planning and learning process. Individuals being involved in the setting of specific goals, monitoring their progress towards the achievement of these goals and the self-evaluation of goals are an area that is strongly supported in research as improving outcomes for autistic adolescents (Hume et al., 2014). Furthermore, through these three evidence-based practices, Kohler et al. (2016) suggested that students would be developing the skills of goal setting, choice-making, problem solving, and self-advocacy, all essential constructs of self-determination. Test et al. (2014) and Wehman et al. (2014) suggested that, while self-determination is a relevant and critical skill for autistic people to have in post-school life, evidence suggests that autistic adolescents often have limited skills in self-determination, and currently are offered few opportunities to develop or use this behaviour skill set throughout secondary education, thereby highlighting the importance of this first category to the transition-focused planning for autistic adolescents. Research conducted within the Queensland and Australian schooling context such as Beamish et al. (2012), Chandroo et al. (2018), and Cumming et al. (2020) all indicate that student focused planning is considered an important category of

The second category in Kohler et al.'s TTP (2016) is student development. This is a critical area in transition planning as it determines which skills will be taught, and how they will be taught, where, and by whom. The practices within this category can generally be considered to fall into the following areas: teaching specific life skills such as cooking, shopping, and leisure skills; teaching functional academic skills such as reading and mathematical skills; teaching employment skills such as completing a job application and job-specific employment skills; teaching self-determination, self-advocacy, and self-management skills; and teaching social and emotional skills (Test, Fowler, et al., 2009). Many of these suggested strategies also indicate that they must be conducted in community or worked-based settings to ensure the generalisation of the skills to the appropriate environmental context (Mazzotti et al., 2014; Test, Fowler, et al., 2009). As suggested by Hume et al., (2014), Test et al. (2014) and Wehman et al. (2014), the effective teaching of adaptive skills is seen as a crucial area of development for autistic adolescents to improve their post-school outcomes. Learning adaptive skills not only improves autistic adolescents' chances of employment but also increases the prospects of their living and functioning in the community independently (Winn & Hay, 2009).

The third category within Kohler's (2016) TTP is family involvement. Even though family involvement in transition planning is anticipated, very few practices to improve the involvement by the families of autistic adolescents in transition-focused education have been identified, and none have a current evidence base to support their use. This is a result of a lack of research, as opposed to the category being less important. Simultaneously, many families also report a lack of involvement in the education of their autistic children (McKinlay et al., 2022), and specifically in the transition planning for their autistic adolescent (Chandroo et al., 2018, 2020). This is concerning for a number of reasons. Family involvement in the transition process has been shown to support more positive educational and behavioural outcomes in autistic adolescents (Kohler & Field, 2003; Mazzotti et al., 2014; Smith & Anderson, 2014). Families with autistic adolescents have been shown to have the highest levels of stress when compared to families with typically developing children or children with other disabilities, particularly in relation to post-school transition (Hume et al., 2014; Smith & Anderson, 2014), and it is well documented that families take on the primary role of finding, organising, and maintaining services and supports after their autistic adolescent has left secondary school (Hendricks & Wehman, 2009; Smith & Anderson, 2014).

Given that families can have such an influential role in the transition-focused education of the autistic adolescent, and that they will continue to be the primary caregivers well into adulthood, it is imperative that educators involve parents in transition-focused education from the very beginning (Mazzotti et al., 2014; Rowe et al., 2015; Smith & Anderson, 2014). Kohler et al. (2016) suggested that this should be accomplished across three areas: participation; empowerment; and training. Participation involves parents being included in all areas of assessment, decision making, goal setting, and evaluation for their child (Rowe et al., 2015). Empowerment and training assist families in learning how to advocate for their child, access and work with support agencies and organisations, and recognise and address needs that are particular to their family (Kohler et al., 2016). With research indicating that the majority of autistic adults, even those without a co-occurring disability, require high levels of parental and family support throughout adulthood, these skills are crucial in supporting post-school options for autistic adults (K. A. Anderson et al., 2018).

Program structures are the fourth category in the taxonomy, and refer to the philosophy, planning, policy, evaluation, and resource development that support the delivery of transition-focused education (Kohler et al., 2016). This category is critical as it refers to the program structures that are set up across education systems and within individual schools that can support teachers to implement evidence-based practices across all other areas of the taxonomy. A strong policy base is imperative (Beamish et al., 2012; Cumming et al., 2020; Kohler & Field, 2003; O'Neill et al., 2016). Given that Australian education does not yet have a policy base for transition-focused education, further practices will need to be identified and implemented in the Australian context to achieve the goal of employing transition-focused education in Australian secondary schools.

The final category is that of interagency collaboration (Kohler et al., 2016). To date, no evidence-based practices have been identified to support the involvement of a range of community organisations, agencies, and businesses in transition-focused education (Test, Fowler, et al., 2009). As with the category of family involvement, this is a reflection on the lack of studies conducted to produce a strong evidence base for this area rather than the lack of importance of the practice. Research indicates that schools and community-based organisations or agencies rarely work together to support students with disabilities when they are in secondary school (Wehman et al., 2014), and that families find interagency collaboration one of the most difficult areas to navigate after their child has left school (Smith & Anderson, 2014; Wehman et al., 2014). This is unfortunate, as Snell-Rood et al. (2020) suggested that interagency collaboration increases the likelihood of positive post-school outcomes for students with autism.

For autistic students in Australian schools, transition-focused education in secondary schools would support the attainment of overarching educational goals while at the same time focusing on the skills required for autistic adolescents to navigate post-school options successfully. Importantly, the TTP (Kohler et al., 2016) provides for both individual characteristics and environmental impacts to be addressed concurrently and addresses one of the key issues with current educational practices: a limited focus on providing appropriate environments (Kuo et al., 2017; Ruble et al., 2019). Of the five domains in the TTP, two focus specifically on addressing the individual skills of students, while the other three address important environmental considerations needed to support the development of students' individual needs, although the implementation of all five domains would provide significant environmental supports for the autistic adolescent.

Student-focused planning and student development both concentrate on developing and enhancing the skills of the individual through the provision of educational strategies. As discussed previously, given that self-determination, organisation and planning, social and emotional skills, and adaptive life skills are the key areas in which autistic students require explicit teaching and support to develop (see Section 2.3 Education), these two categories are crucial for the appropriate education of autistic adolescents. The other three categories – family involvement, program structures and interagency collaboration, do not focus on developing the individual skills of the adolescent; rather they provide the structures, support, and knowledge necessary for teachers and parents to support the development of the student's skills. As discussed previously, within the biopsychosocial model of disability, this is a critical aspect of supporting outcomes for autistic individuals, with much research showing the significant impact that environment can have on individual outcomes (Howlin, 2021; Thompson et al., 2018). Consequently, the TTP (Kohler et al., 2016) shows a high level of relevance for supporting autistic adolescents in schools to transition to positive post-school outcomes.

Australia does not have a strong legal framework that focuses on the rights of people with disabilities in education such as that seen in the United States with the Individuals with Disabilities Education Improvement Act and the No Child Left Behind Act (Beamish et al., 2012; Winn & Hay, 2009). These policies act to mandate the requirements and expectations of schools to provide appropriate, evidence-based programs, support, and interventions to improve the post-school outcomes of people with disabilities (Mazzotti et al., 2013; Mustian et al., 2012). In Australia, the Alice Springs (Mparntwe) Education Declaration (Education Council, 2019) and the Disability Standards for Education (Australian Government, 2020) serve as the primary guides for how educational facilities support the rights of people with disabilities. Although both documents refer to the importance of young people's transition from school to post-school and to the importance of system- and school-wide supports for individual development, the documents do not outline when, how, or by whom specific transition-focused expectations will be put into place. Furthermore, the Queensland Education Department has only two documents relating to supporting students who experience disability: the *Every student with disability succeeding plan 2021-2025* (Queensland Government, 2021a); and the

Transition to post-school for students with disability (Queensland Government, 2021d). Again, the documents do not outline when, how, or by whom specific transition-focused expectations will be put into place, nor do they encourage the use of the TTP (Kohler et al., 2016) or any other transition-focused education framework.

The use of transition-focused programming for students who experience disabilities in the United States has been written into national and state educational policies for many years (Plotner et al., 2015), and, while it is not yet written as a priority in Australian education legislation, the expectation that teachers will use transition-focused programming is starting to filter through the Australian state education systems (Cumming et al., 2020; O'Neill et al., 2016). As much of the professional development and literature used throughout Australia is developed in the United States, education researchers and practitioners in Australia are familiar with the term ***transition-focused education*** and use the term to describe and discuss the various practices that are used. Without policy support, however, there is concern as to whether the term is being used consistently, and whether teachers are aware of the actual evidence base for the transition-focused educational practices that they are using (Cumming et al., 2020).

In the Beamish et al. (2012) study of Queensland schools, participants were asked to rate their level of agreement with transition-focused practices taken from the TTP (Kohler et al., 2016), and their level of implementation of these practices. Although the findings indicated that Queensland teachers strongly agreed with the practices suggested in the TTP, the rates of implementation of these practices were much lower. The highest frequency of implementation was evident in family involvement, with the lowest rates of implementation in interagency collaboration and program structure (Beamish et al., 2012). This suggested that there are low levels of staff and parent training and empowerment, student-focused planning, student development practices, interagency collaboration, policy support, and strategic planning in transition-focused education across all Queensland secondary schools. Thus, in Australian and Queensland policy, there is currently no mandate, nor expectation, that teachers will use transition-focused programming with students with disabilities, or with students on the autism spectrum, throughout their secondary school education. This would suggest that the use of transition-focused education throughout secondary school would be very limited for autistic adolescents in Queensland and may be contributing to the poor post-school outcomes of these students.

The effectiveness of transition practices for supporting more positive post-school transitions for students with disability has been consistently shown through research. From the development of the TTP framework (Kohler, 1996), to studies conducted by Hendricks and Wehman (2009), Wehman et al. (2014), Carter et al. (2014), Hatfield et al. (2018), Snell-Rood et al. (2020), and Chun et al. (2022), research indicates that strong, effective transition practices support positive QoL in post-school options for young people with disabilities. Although most research conducted focuses on the broader category of disability, some studies such as Hendricks and Wehman (2009) and Westbrook et al. (2015) have focused specifically on transition practices supporting autistic adolescent's transitions. Additionally, more recent research has begun to consider how this research translates to the Australian educational experience (Beamish et al. 2012, Chandroo et al., 2018, 2020; Cumming et al., 2020; O'Neill et al., 2016; Strnadova and Cumming, 2016).

Despite these consistent findings, however, the majority of these studies are qualitative, and there remains a lack of studies supported by rigorous experimental designs to determine the exact requirements of transition focused education to produce optimum QoL outcomes for young adults with (Westbrook et al., 2015). Test et al. (2009) and Mazzotti et al. (2014) have identified and compiled a list of transition practices that show a moderate level of evidence for effectively supporting the transition of students with disability. This list uses the TTP framework to identify skills that should be taught in secondary school to support post-school transition. It is provided on the National Secondary Transition Technical Assistance Center (NSTTAC) and is accessible to secondary school teachers worldwide through the NSTTAC website.

Importantly, all research on transition to post-school options for students with disability, including students on the autism spectrum, has shown a range of enabling factors for implementing effective transition practices. These factors include – the importance of a collaborative, team-based process (Carter et al., 2014; Snell-Rood et al., 2020; Wehman et al., 2014) which requires effective and consistent communication and support for families (Kirby et al., 2020); a focus on developing social, functional, and community-based skills such as self-care, employment, and communication skills (Elias et al., 2019; Hatfield et al., 2018; Westbrook et al., 2015); and a focus on the active involvement of the autistic individual in the transition planning process (Chandroo et al., 2018; Hatfield et al., 2018).

Although these considerable levels of research supporting the use of transition practices to support post-school QoL exist, contemporary research still found that effective transition practices were not being used consistently, both across international literature (Chun et al., 2022), and Australian literature (Bruck et al., 2021). Thus, a 'research to practice' gap remains with the implementation of consistent, effective transition practices for autistic students as they prepare to move to post-school options.

2.5. Post-school Outcomes

During this period of transitioning from school to post-school options, or transitioning from adolescence to adulthood, young people's focus turns to accepting responsibility for oneself, making independent decisions, and becoming financially independent (Arnett, 2014). For many autistic people, however, the goal of living a fulfilling, productive, and independent life does not become a reality. Autistic people are reported as having some of the poorest QoL across all areas of post-school life when compared both to people diagnosed with other disabilities and to people without disability. This includes low rates of employment and independent living, poor levels of adaptive functioning, and few quality relationships outside the person's family (Bishop-Fitzpatrick et al., 2016; van Heijst & Geurts, 2015; Winn & Hay, 2009).

2.5.1. Employment

Taking responsibility for oneself and becoming financially independent is for young adults to gain employment and is considered to be a fundamental aspect of adulthood, "Work is, in all cultures and in all historical contexts, one of the fundamental areas of human activity" (Arnett, 2014, p. 329). Within Western cultures such as Australia, paid employment is the main work performed and allows adults to have the financial means to choose to live independently and to make decisions for themselves (Cheak-Zamora, Teti, Peters, et al., 2017; Solomon, 2020). Regrettably, young adults on the autism spectrum are at significant disadvantage in gaining and maintaining paid employment and this, in turn, impacts on their level of independence. As discussed in Chapter 1, the Australian Bureau of Statistics (2019) reported that just 38% of autistic adults are employed, fewer than half compared to their nonautistic peers at 84.1%. Furthermore, autistic adults have a corresponding unemployment rate of 34.1%, more than seven times the unemployment rate of nonautistic adults at 4.6%. Flower et al. (2021) also found that those autistic adults who are employed are more likely to be underemployed, that is, to work not as many hours as they would like or to work in jobs beneath their education level. Importantly, these employment outcomes are not related to an individual's intellectual functioning but are consistent for adults on the autism spectrum both with and without a co-occurring intellectual disability (ID) (Anderson et al., 2021).

Research conducted on employment for people on the autism spectrum has focused on why employment is so important to autistic adult outcomes, which factors affect employment for autistic individuals, and how best to support positive employment outcomes for them. Mai et al. (2019) stated that, as with all adults, working improves the financial status of autistic adults, which improves their overall QoL by allowing them to live where they choose, provide for their own needs, and engage in activities that they value. Farkas et al. (2021) added to this by suggesting that employment also offers other gains, including "social identity, social contacts and support, a means of structuring and occupying time, activity and involvement and a sense of personal achievement" (p. 3). These gains can be significant, with Solomon (2020) reporting that employment improves the subjective wellbeing of autistic adults by as much as 30%. Conversely, unemployment has been associated with increased social exclusion, poor mental health, and poor QoL (Billstedt et al., 2011), including an increased risk of homelessness, and the person needing more access to support services, as well as a reduction in the daily living skills and social skills that may have been gained during school or previous employment (Solomon, 2020). It has also been suggested that the unemployment of autistic adults can increase the financial and personal impact on their family and community. Thus, unemployment negatively affects individuals, their family, and the wider community, while employment offers positive aspects across all stakeholders (Jacob et al., 2015).

Despite the researched benefits of employment, it still remains the case that autistic adults experience difficulties finding a job, and, once they do so, they also experience difficulties maintaining this employment (Farkas et al., 2021). Research about why this is the case has traditionally focused on the characteristics of people on the autism spectrum that make gaining and maintaining employment difficult. The core characteristics of autism, differences in social communication and differences in behaviour, are both suggested to impact on employment opportunities. Bury et al. (2021) found that, overall, autistic individuals find the social aspects of workplaces difficult, tiring, and stressful. Regardless of job type, or the person's job-related skills and abilities, the ability to communicate effectively and to engage socially with customers/clients, work colleagues, and supervisors is accepted as critical to all workplaces. Differences in how autistic individuals both use and process communication (Howlin, 2021), and the different ways that they engage in social exchanges, can result in a significant number of difficulties in the workplace. This includes but is not limited to misunderstanding tasks; not understanding the 'hidden curriculum' of the workplace such as when, where, and of whom to ask questions; not engaging in the social communication expected such as greeting customers or colleagues; and not being able to ask for required accommodations or for help as needed. Waisman-Nitzan et al. (2020) found that the most common difficulty in the workplace described by autistic adults was the mismatch between the social communication expectations in the workplace and the individual's abilities and interests in social communication. Furthermore, Flower et al. (2021) and Bury et al. (2021) found that social and communication differences in the workplace were not seen as a potential workplace advantage in any circumstances. That is, differences in communication and social skills were seen negatively, with no potential positives being attributed to these core characteristics.

Rigid and repetitive behaviours and interests, another core characteristic of autistic people that often translates into intense, specific interests and an ability to focus for long periods of time, are seen to have both positive and negative outcomes in the workplace. Bury et al. (2021) found that abilities such as focusing for long periods of time, superior attention to detail, high levels of interest in a specific topic, and a preference for engaging in repetitive tasks are a significant advantage for some autistic people in some workplaces. Many people on the autism spectrum report that a lack of structure in the workplace and changeable and unpredictable work environments can make the workplace difficult to manage (Dreaver et al., 2020). Although Waisman-Nitzan et al. (2020) reported a negative correlation between special interests and work performance, this was suggested to be a result of the mismatch between work requirements and the amount of time that the person was able to spend on the special interest, rather than of the special interest itself.

Additional characteristics common to autistic individuals that can result in difficulties in the workplace include sensory sensitivities and executive functioning difficulties. Although not considered a core characteristic of autism, sensory reactivity differences are a common experience for autistic traits (MacLennan et al., 2022). These differences in how autistic individuals experience sensory inputs can result in the individual experiencing challenges in some work environments. For example, workplaces that are very loud, have bright lighting, particular smells, or result in close proximity of people, are reported to be a challenging experience by some autistic individuals (Solomon, 2020). Additionally, executive functioning difficulties in areas such as goal-driven independent behaviour, including planning, executing actions, and determining next steps, can also negatively affect some autistic individuals. This can result in difficulties in developing and maintaining independence and self-efficacy in the work environment, as the individual is likely to require structure and support at each step of the work task (Scott et al., 2017). From the employer’s perspective, these potential increases in supervision can have high financial and time costs and reduce productivity (Solomon, 2020).

Although research has indicated individual autistic characteristics that may make gaining and maintaining employment difficult, research has also shown that the level of support and interventions provided in the workplace has a significant impact on the employment outcomes of autistic individuals (Mai, 2019). Thus, the more contemporary research focus has shifted to also considering the environmental reasons why autistic people are not employed. Mai (2019) found in her study of hiring agents’ attitudes towards hiring autistic candidates that hiring agents believe that autistic individuals will be difficult employees who are less dependable and capable than nonautistic employees. Because hiring agents believe that their "responsibility is to find qualified employees who will work well with their co-workers" (Mai, 2019, p. 9), the social stigma caused by stereotyping of and discrimination against autistic individuals reduces their opportunities for employment, regardless of their levels of intellect or job-specific skills (Scott et al., 2017). Furthermore, when autistic individuals do experience challenges in the workplace, both supervisors and employees attribute their workplace social challenges to internal factors such as autistic characteristics, rather than external factors such as workplace culture, broader communication issues, or the lack of provision of reasonable adjustments (Bury et al., 2021). As a result, autistic adults experience both individual and environmental factors that affect their opportunities to gain paid employment.

Conversely, many factors have been identified that can increase opportunities for the employment of autistic adults. Lorenz et al. (2016) suggested that, when a strengths-based perspective is taken, that is ensuring that the right person is employed in the right job, the employment of autistic adults can provide significant benefits. For this to occur, it is necessary to focus on the individual characteristics and strengths of adults, while also considering the barriers that might occur for them in the workplace and providing appropriate accommodations, including training for employees, their supervisors, and their work colleagues (Milton & Sims, 2016). When these conditions occur, both Scott et al. (2017) and Solomon (2020) found that employers reported that their autistic employees provided high levels of trustworthiness, integrity, reliability, attention to detail, and low absenteeism. Overall, the impact of having an employee on the autism spectrum in the workplace was overwhelmingly positive. Furthermore, it was seen to create a culture of inclusion in the workplace, and to promote corporate social responsibility (Scott et al., 2017).

2.5.2. Postsecondary Education

A key factor that improves opportunities for employment for autistic adults is education. As discussed previously, autistic children and adolescents tend to struggle in contemporary educational contexts, and as a result, many autistic adolescents complete school with lower academic achievements and fewer social and emotional skills (Arnett, 2014). These lower levels of achievement affect not only employment opportunities but also opportunities to attend postsecondary education such as university or Technical and Further Education (TAFE) institutions, thereby further affecting employment opportunities. In Western cultures such as Australia young people generally have high levels of access to education, including secondary and postsecondary education, with a wide range of occupations requiring postsecondary levels of education (Arnett, 2014). For young people who experience disadvantage such as those on the autism spectrum, these opportunities for postsecondary study and consequent employment are limited. In Australia, only 8.1% of young people on the autism spectrum have a bachelor degree or higher, compared to 16.1 % of people with all disabilities and 31.2% of people with no disability (Australian Bureau of Statistics [ABS], 2019). When combining this with the statistics that show that employment rates are higher for people with post-school qualifications than without post-school qualifications (Australian Bureau of Statistics, 2021), the overall impact becomes significant. This was further supported by Autism Spectrum Australia (ASPECT) (2013), which found that unemployment rates fell from 69% for young autistic adults with a Year 10 standard of education, to 40% for those who completed Year 12, to 34% for those who completed a bachelor degree or higher. While these unemployment figures are still too high, the value of postsecondary education for life-time outcomes for individuals on the autism spectrum cannot be overstated, with strong positive relationships shown among postsecondary study, employment outcomes, and financial wellbeing (Mulder & Cashin, 2014).

Fortunately, there has been a significant increase in the number of young people on the autism spectrum attending and requesting support in postsecondary education settings (Anderson et al., 2020), although graduation rates continue to be low (Anderson et al., 2017). As with employment, there are many factors, both individual and environmental, that influence young autistic adults' participation and success in postsecondary education. These factors relate to the mismatch between the core characteristics of people on the autism spectrum and an environment that was designed for nonautistic students. Contemporary views around inclusion are beginning to challenge the "assumption of who belongs [to] and who can benefit from tertiary education" (Mulder & Cashin, 2014, p. 666); however, postsecondary education processes and structures are still not compatible with all learners.

Factors relating to academic challenges highlight the mismatch between core autistic characteristics and postsecondary education expectations. A key factor influencing outcomes is the difficulty that the autistic person experiences with social communication in the postsecondary educational environment. The communication aspect affects some people's ability to understand ambiguous concepts, to process large amounts of verbal or written information quickly, and to ask questions to clarify understanding (Cai & Richdale, 2016). Challenges in social academic skills can include difficulties with group work, presentations, and using social skills during classes (Anderson et al., 2020). Combined, these social communication challenges result in many autistic students being unable to engage effectively in learning and to demonstrate their knowledge about the topics that they are studying. Additionally, problems with executive functioning (Dijkhuis et al., 2020) and sensory sensitivities (Anderson et al., 2017) were also indicated as presenting difficulties in academic learning. As many students on the autism spectrum experience difficulties with executive functioning, they can struggle with organisational and time management tasks such as attending classes on time, planning out steps to complete assessments, and the timely submission of assessments. The lack of structure in the postsecondary educational environment means that the entire responsibility for this planning is placed on the individual, and autistic students identified this as one of the main reasons that they do not succeed in their studies (Cai & Richdale, 2016). Autistic students have also reported that they often find the postsecondary educational environment overstimulating, and struggle to manage their sensory sensitivities alongside learning and communicating in the social environment (K. A. Anderson et al., 2018).

Despite these considerable challenges with academic success for postsecondary students on the autism spectrum, research conducted on the experiences of these students has shown that the main challenges are non-academic. Autistic students in postsecondary education report high levels of emotional challenges such as anxiety, depression and poor overall mental health, and social difficulties such as isolation and loneliness (Gelbar et al., 2015). Furthermore, these non-academic challenges are more poorly understood and supported less effectively in the postsecondary educational environment (Anderson et al., 2020). As a result, these non-academic challenges are likely to have negative impacts on both the academic performance and the overall wellbeing of the young adult. The cyclical nature of academic and non-academic challenges, and the impact that this has on long-term success, has been shown to be a key aspect of school-age education (Saggers et al., 2019). Furthermore, the interactive nature of these challenges for postsecondary students on the autism spectrum have not yet been made clear through research.

Anderson et al. (2018; 2020) and Ward and Webster (2018) all indicated that self-advocacy is a key factor in the success or non-success of autistic students in postsecondary education. Self-advocacy skills can ensure that young adults are provided with the correct support to facilitate their engagement and success in the postsecondary educational environment, and to support awareness in staff and peers, thus facilitating a more inclusive experience. Conversely, poor self-advocacy skills can result in a lack of understanding, support, and inclusion. The significant challenge in postsecondary contexts is that the onus is on students to self-identify as autistic, to seek and request support, and to advocate for the accommodations that they require (Mulder & Cashin, 2014). Many young autistic adults start university without these self-advocacy skills, choose to wait and "see how they go" first, or are reluctant to disclose their autism diagnosis (Mulder & Cashin, 2014, p. 667). Because of this, many autistic students will disclose their need for support only after a crisis occurs rather than at enrolment (K. A. Anderson et al., 2018; Anderson et al., 2020; Cai & Richdale, 2016). Often students are so distressed at this point that they choose to leave postsecondary studies, rather than seek support (K. A. Anderson et al., 2018).

A key consideration with self-advocacy and accessing appropriate support is the transition into postsecondary education. Mulder and Cashin (2014) identified that there were no formal transition programs from secondary school to university in Australia, and it can be assumed that for students enrolling in university as mature age students this would also be the case. Thus, autistic students enrolling in university for the first time have had no formal transition plan, are either not aware of or do not know how to access available support, and do not feel prepared to self-advocate for these supports (Anderson et al., 2020). As a result, most young adults state that they do not feel adequately prepared to attend postsecondary education (Cai & Richdale, 2016). In the majority of situations where young adults do disclose their autism diagnosis at enrolment and access support from the beginning of their postsecondary journey, parents were significantly involved in the process (K. A. Anderson et al., 2018; Cai & Richdale, 2016).

Irrespective of the many challenges that young autistic adults' face throughout postsecondary education, they also possess many positive individual traits and strengths that support good educational outcomes. University students surveyed in the Anderson et al. (2018) study described a range of positive strengths and traits. These included their intense interest in the subject that they are studying, and also having good attention to detail, original and creative ideas, a strong memory, and strong technology skills. Each of these characteristics is well recognised as being positive traits in many autistic individuals, and they are also characteristics that are highly relevant to postsecondary education (K. A. Anderson et al., 2018). Structures and supports that utilise and highlight these strengths, while at the same time reducing challenges are those that are most likely to result in positive educational and social outcomes for young autistic adults.

Many universities across Australia have developed and implemented support for young adults with disability during their postsecondary education. These include a range of accommodations such as campus orientation, extensions for assignments, examination accommodations, tutors, scribes, and the development of individual support plans (K. A. Anderson et al., 2018; Anderson et al., 2020). While these accommodations focus on supporting academic outcomes and are reported to be helpful by students on the autism spectrum (Anderson et al., 2020), the main challenges faced by young autistic adults fall into the non-academic areas such as communication, social engagement, and self-advocacy. As a result, some universities have also implemented autism specific supports for social skilling, communication, dealing with anxiety, and sensory friendly spaces on the campus. Students on the autism spectrum reported in the Cai and Richdale (2016) and the Furuhashi (2021) studies that these non-academic supports were very helpful, especially when they were provided by peer mentors or in group support situations.

A key aspect of providing appropriate support for postsecondary students on the autism spectrum is self-advocacy. As discussed previously, without self-advocacy even when supports are available, they are unlikely to be used by the students who need them. Given that many young people on the autism spectrum report that they struggle with self-advocacy (Anderson et al., 2020), finding alternative ways to advocate for these young people becomes critical. Cai and Richdale (2016) reported that family support was considered essential by the majority of young adults who were interviewed. This support included organisational, emotional, and financial support but more importantly, also included parental advocacy at the postsecondary institution during enrolment. In this way, the institution was able to employ appropriate assistance for engagement and learning that supplemented the external family support already provided. Overall, this was described by young people as resulting in a more positive experience of postsecondary education (K. A. Anderson et al., 2018), and resulted in more successful outcomes (Cai & Richdale, 2016). Thus, some young autistic adults have stated that increased options for parental advocacy would be beneficial. For others, this is viewed as reducing their autonomy and chance for self-advocacy (K. A. Anderson et al., 2018), which indicates that parent advocacy would need to be provided in the context of student choice. Alternatively, effective transition practices that include proactive support for self-advocacy by the individual and greater initiation of support by the institution may be appropriate.

2.5.3. Independent Living

Independent living is a basic human right and an important aspect of overall wellbeing and independence for autistic individuals (Hewitt et al., 2017). Independent living "enables individuals to determine where they live, whom they live with and what kind of support they receive" (Ghanouni et al., 2021, p. 1). It is important to acknowledge that this does not mean that the young adult must do everything on their own; rather it emphasises their choice in where and with whom they live. When compared to nonautistic adults, or adults with other disabilities, a higher percentage of people on the autism spectrum live in their family home, while a smaller percentage lives in either supported living houses or their own home. In the United States, Hewitt et al. (2017) found that 46.1% of adults on the autism spectrum live in their family home, 4% live in institutions and only 8.4% live in their own home. This was compared to 15% of people with other disabilities who live in their own home. While there are no current data available for rates of independent living in Australia, a study conducted by Gray et al. (2014) across two Australian states, New South Wales and Victoria, showed that 61% of autistic adults lived in the family home while 9% lived independently. This finding suggested that, both internationally and in Australia, a very small number of autistic adults live independently in their own homes, while the majority continue to live in the family home with their parents. Furthermore, Hewitt et al. (2017) reported that the number of people on the autism spectrum living in the family home continues to increase.

Autistic individuals' core characteristics in the areas of communication, social interaction, and behaviour are well recognised and often discussed in relation to difficulties experienced with employment, postsecondary education, and independent living. Each of these area falls under the heading of adaptive behaviours. Adaptive behaviours were defined by Baker et al. (2021) as "behaviours that include the development of personal independence and social responsibility necessary to care for oneself and interact with others in a variety of environments" (p. 2). Within these adaptive behaviours, daily living skills such as personal hygiene, cleanliness, financial responsibility, meal preparation, and time management are considered critical to independent living (Baker et al., 2021). For people on the autism spectrum, the core characteristic differences in social communication and rigid and repetitive behaviours and interests, combined with the secondary characteristics of executive functioning difficulties and sensory sensitivities, mean that many autistic individuals struggle to develop the adaptive behaviours and daily living skills necessary for independent living in adulthood (Kanne et al., 2011; Matthews et al., 2015; Nyrenius & Billstedt, 2020). While Baker et al. (2021) found that 75.6% of autistic participants in their study fell below the adequate range on the Vineland Adaptive Behaviour Scales (Sparrow et al., 2016), Kanne et al. (2011) and Nyrenius and Billstedt (2020) indicated that the gap between cognitive functioning and adaptive functioning increases with age. This suggests that autistic adolescents and autistic adults may experience greater levels of difficulty in acquiring and using the adaptive functioning skills needed for independence than younger individuals, further impacting on their transition from school to post school options.

These findings were supported by Duncan et al. (2022), who found that adolescents on the autism spectrum develop daily living skills at a slower rate than their nonautistic peers, and that the gap between autistic individuals and their peers widens as they move into adulthood with the development of daily living skills plateauing for autistic individuals. Thus, if autistic adolescents do not develop functional adaptive behaviours during this developmental transition period, they are at increased risk of having lower levels of adaptive behaviours and daily living skills in adulthood. Concurrently, Ghanouni et al. (2021) suggested that, even when the young adult does have the skills to manage a large number of daily living skills, the uncertainty and change that come with this in independent living situations can result in burnout without the appropriate support.

Parents and carers routinely describe the poor adaptive functioning of their autistic adult children, and the significant impact that this has on their ability to manage independent living. They face the difficult balance of allowing their young adult child to live independently while ensuring their safety and wellbeing. Stakeholders are aware of this conundrum, but they typically struggle to know how to address it (Ghanouni et al., 2021). Parents in the Ghanouni et al. (2021) study acknowledged their young adult child’s need for autonomy and to live independently, while at the same time expressing concerns about the young adult’s ability to manage her or his own health and wellbeing, safety, finances, and autistic characteristics such as sensory sensitivities. Interestingly, in this study the young adults themselves expressed very similar concerns. While they wanted to live independently, they questioned their own ability to manage it. For some participants, this resulted in the autonomous choice to remain living with their families, while others saw it as something that they would need to work towards for the future.

One key aspect of independent living that both parents and autistic adults raised in the Ghanouni et al. (2021) study was financial autonomy. Difficulty with managing finances was suggested by participants to be one of the core elements that negatively affected independent living in adults on the autism spectrum. Cheak-Zamora et al. (2017) conducted interviews with adolescents and young adults on the autism spectrum and found that autistic individuals defined independence as being able to manage their finances, but they worried about their lack of money management skills and cited poor financial skills as a barrier to their independence. Again, although many families were willing to support their young adult children with managing their finances, this was seen by both parents and young adults as resulting in a loss of financial autonomy by the young adult (Ghanouni et al., 2021).

Despite these difficulties with adaptive behaviours and daily living skills, it is important to note that daily living skills change over the lifespan for all individuals and are amenable to intervention (Baker et al., 2021; Duncan et al., 2022). Thus, incorporating the explicit teaching of these skills can enhance autistic children's, adolescents', and young adult's adaptive skills, gradually increasing in complexity as they move into adulthood. A study conducted by Duncan et al. (2022) showed that young adolescents can make significant gains on adaptive skills such as personal hygiene and cleanliness, time management and engaging in independent activities when provided with an explicit teaching program focusing on these skills. The program incorporated working with both the adolescents and their parents to teach the skills and to develop strategies for generalising these skills to everyday life. While the findings were very positive and the adaptive skill increases were significant, the development of adaptive skills did not continue after the program finished. This indicates that the continued teaching of new skills and the extension of skills learned over the long term may be necessary to improve long term independence (Duncan et al., 2022). Worryingly, both Hewitt et al. (2017) and Ghanouni et al. (2021) indicated that opportunities for the long-term teaching of adaptive skills and for the consequent improvements in independent living skills are rarely available for adolescents or young adults on the autism spectrum.

2.5.4. Social Participation

Human beings exist in a social world and, as such, much of what is done as a human involves participation in this social world. Participation in family groups, friendship groups, employment, and educational experiences all incorporate high levels of social interaction and the need to belong to and be accepted by social groups is considered a basic human need (Ryan & Deci, 2017). Furthermore, research across all ages, societies, and demographics has consistently shown that high levels of social participation results in more positive wellbeing and outcomes for individuals (Ryan & Deci, 2017). Thus, it can be inferred that this basic psychological need is also relevant to autistic individuals, and that higher levels of social participation will support more positive wellbeing and outcomes for them (Morrison et al., 2020). While this may be true, research consistently finds that individuals on the autism spectrum experience persistent social participation impairments and have high rates of social isolation, and consequently low levels of wellbeing and poor outcomes (Hancock et al., 2020; Mattys et al., 2018; Orsmond et al., 2013).

These low levels of social participation and the resulting outcomes are equally relevant to young adults on the autism spectrum as they transition from school to post-school options. Orsmond et al. (2013) found that social participation does not appear to change as the young person navigates the contextual changes that occur across this transition. Young autistic adults experience low rates of social participation in the early post-school years, just as they do in their secondary school years, with over one third of young autistic adults in the Orsmond et al. (2013) study indicating they had no contact or phone calls with friends, and received no invitations to, or engaged in, any social activities. When these social participation outcomes were compared to those of young adults with other disabilities such as intellectual disability, learning disability, and emotional disorders, Orsmond et al. (2013) found that adults on the autism spectrum experience uniquely high levels of social isolation compared to all others. To combine these findings with the extremely low rates of employment and postsecondary study, as discussed above, the significant social isolation experienced by many young autistic adults becomes clear. This is especially concerning given that “this life stage presents a potentially crucial turning point in the maintenance and development of social relationships” (Orsmond et al., 2013, p. 2711) for the remainder of the adult lifespan.

Research and interventions addressing these low levels of social participation have traditionally focused on the individual impairments of the autistic individual, and on the impact that these have on social participation (Milton, 2012). The combination of social impairments, communication impairments and restricted and repetitive behaviours and interests was seen to result in reduced social skill levels, which meant that the autistic individual was unable to participate socially in a typical nonautistic community and to maintain friendships or romantic relationships. Taking this evidence and considering it within the medical model of disability, according to which the impairment exists entirely with the individual, the assumption was made that it was an autistic person’s preference not to engage socially and that they had no interest in social inclusion (Waldock, 2019). In fact, comments addressing autistic people and their social inclusion often included that they prefer things to people and that they like to be on their own.

More contemporary research, however, is beginning to challenge these assumptions. With stronger levels of advocacy from autistic people, research has focused more on the ideas and perceptions of the autistic community than on collecting evidence from those around them such as parents, teachers, and medical professionals (Hong et al., 2016). This change in how research is conducted has in turn influenced the outcomes of the research. Mattys et al. (2018) discovered in their research on the important factors that young autistic adults attribute to their wellbeing, that is, the responses by their autistic participants were very socially oriented. In this research the young adults identified that friends were of significant importance to them and that they were "motivated to establish and maintain relationships with real friends" and engage in romantic relationships (Mattys et al., 2018, p. 328). Conversely, these young people also described the significant difficulties that they had in understanding how to establish and maintain friendships and relationships and the difficulties that this created for them in forming their social identity as an adult. Thus, while social relationships were highly valued, they were also something with which young adults experienced significant difficulties.

Hancock et al. (2020) found very similar findings to this in their comparison of autistic and nonautistic individuals in relation to the interest in and success with romantic relationships. Overarching findings indicated that, while individuals on the autism spectrum express the same desire for friendships and romantic relationships as nonautistic adults, they report that they have fewer friends and fewer experiences in romantic relationships. Furthermore, it was also found that reduced autism characteristics do not increase the likelihood of being in a romantic relationship, so these findings hold true for individuals regardless of the level of presentation of their autistic characteristics. Interestingly, the Hancock et al. (2020) study also showed a bidirectional relationship between opportunities to establish relationships and having the social skills and confidence required to establish relationships. Reduced opportunities to meet new people, through limited employment, post-school education, and social activities, reduce the opportunity to develop and gain skills and confidence in social interactions. In turn, limited skills and confidence in social interactions further reduce the chance that autistic adults will choose to engage in social interactions and relationships.

Additionally, Morrison et al. (2020) reported that findings from their study on the outcomes of real work social interactions with autistic adults indicated that nonautistic adults tend to form more negative first impressions of autistic adults, and as a result are less likely to pursue social interactions with them. From this perspective, the social difficulties experienced by adults on the autism spectrum occur not only because of the discrete characteristics of the individual but also from a lack of fit between those characteristics and the specific social environment (Morrison et al., 2020). Milton (2012) discussed these findings in the context of the "double empathy problem" (p. 884), which suggests that the communication and social gap that exists between autistic and nonautistic individuals is not a result of the autistic person's lack of communicative or social skills. Rather, it is a result of the fundamental differences between the autistic experience of social interactions and communication and the nonautistic experience, thus, creating a situation where neither fully understands the perspective of the other and both struggled to display empathy with and understanding of the other's motives in their communication and social interactions.

This was supported by Morrison et al. (2020), who proposed that, if social impairment is intrinsic to the autistic person, social interactions between two autistic individuals would be poorer than between autistic and nonautistic individuals. This was not the case. For participants in the study, it was found that higher levels of acceptance and compatibility were shown between two autistic participants engaged in social interactions than between autistic and nonautistic participants. Furthermore, autistic participants indicated more interest in future interactions with autistic individuals than with nonautistic individuals. Overall, findings from this study indicated that autistic adults have a similar level of social motivation to that of nonautistic people and show the same level of social awareness for interpreting social situations as nonautistic people, but also appear to show a higher level of compatibility with autistic peers. This provides substantial evidence to support the more contemporary belief that social difficulties for autistic people are related to social contexts rather than to individual deficits and suggests an unmet need for social experiences for people on the autism spectrum (Sasson et al., 2017).

2.5.5. Quality of Life

Each of the outcomes addressed above combines to create the overall concept of quality of life (QoL). The QoL framework is a structure in which various indicators are used within eight domains to conceptualise and assess the QoL of the individual. The eight domains are: emotional wellbeing; material wellbeing; physical wellbeing; interpersonal relationships; social inclusion; human and legal rights; personal development; and self-determination (Schalock, 2004). Although the QoL framework has undergone much debate in relation to the specific indicators used within each of these domains, the domains themselves have remained stable over the years and through much research (Schalock, 2004). The framework has been shown to provide a systematic structure and a common language for considering the overall wellbeing and level of satisfaction of the individual across a range of cultures and contexts (Schalock, 2020) and a number of disability categories, including autism (Renty & Roeyers, 2006). Over the years, the QoL framework has increasingly been used for research and application in the field of education. It is considered valuable when determining the experience of individuals within specific contexts; is the individual experiencing a positive QoL, and, in assessing the effectiveness of programs in terms of outcomes for the individual, does the program improve QoL? This different focus within assessments is described as either objective or subjective measurements (Erez & Gal, 2020; Schalock, 2004).

Objective QoL refers to a comparison of the individual's standing against the norm or average for people of that age in a specific domain. For example, the expectation in Australia is that adults will be employed and support themselves financially; therefore, being employed is rated as good QoL, while being unemployed is rated as poor QoL. Subjective QoL refers to how the individual feels about their current experience in a specific domain. For example, whether individuals feel valued in their current employment, or if they believe that the wage or salary earned allows them to support themselves financially. The relationship between objective measures and subjective measures is modest, with the key differences suggested to result from the individual's values and aspirations (Erez & Gal, 2020). That is, if the individuals are not employed, but they do not want to be employed, they are unlikely to view this as a negative outcome, and satisfaction of

QoL will not be impacted. The value of the QoL construct is that it has been used historically to measure both the objective outcomes of people who experience disability, such as employment rates of people with specific disabilities, and the subjective outcomes as a way of improving and enhancing the overall sense of wellbeing of an individual with disabilities (Schalock, 2020).

Objective views of QoL have tended to view the concept as a single entity: individuals either have good QoL or they do not. For example, an individual is either employed or unemployed. More contemporary understanding support QoL as a multidimensional concept that can change over time and in different environments (Lombardi et al., 2019). For example, young people may experience poor QoL in educational environments because they do not enjoy being inside, struggle with reading, and find social relationships difficult. They may then experience a good QoL working as a jackaroo, for example, mustering cattle on a farm in the outdoors with only one other person. Thus, the measurement of subjective QoL has taken on greater emphasis. Schalock (2000) indicated that subjective QoL is the most appropriate measure when the focus is on the individuals' perception of their QoL rather than on how their QoL compares to prescribed standards.

It has been argued that the very definition of QoL implies its subjective nature (Oakley et al., 2021). That is, considering the individual's perception of QoL (World Health Organization, 1995) necessitates that any assessments take an emic perspective of QoL and mirror the individual's perceptions and values (Erez & Gal, 2020). This is considered particularly relevant for people on the autism spectrum, especially in light of the double empathy problem (Milton, 2012). Waldock (2019) stated that it "remains unclear as to what extent neurotypical definitions of a 'good QoL' may be applicable to an autistic person" (p. 77) with an acknowledgement that the experience of autism is fundamentally different from that of a nonautistic person. Furthermore, it is suggested that objective measures need to be used with caution as, while they are valuable in certain situations, comparison against a prescribed norm that relates to the values of nonautistic people is used.

The different results obtained between objective and subjective measures of QoL is becoming evident across research conducted on the QoL experienced by autistic individuals. Research into QoL for autistic individuals has traditionally used objective QoL measures and been collected through proxy reports, or reports completed by someone on behalf of the autistic individual, usually a parent (Bishop-Fitzpatrick et al., 2016; Hong et al., 2016). Although there has been some variability within the findings, the understanding that has emanated from this research is that autistic individuals experience poor QoL across all domains compared to nonautistic individuals and to individuals with other disabilities (Bishop-Fitzpatrick et al., 2016; Clark et al., 2015; Hong et al., 2016). These findings have been consistent across the lifespan, for children, adolescents, and adults on the autism spectrum, and relate to a variety of environmental contexts, including both school and post-school (Clark et al., 2015; Oakley et al., 2021).

The more recent focus on increased autism advocacy has seen changes in how research is conducted, and as a result, differences in QoL assessment outcomes for autistic individuals. Two key factors in this change included the move from using objective to subjective QoL measures, and the increased use of self-reports, or reports provided directly by the autistic individual themselves (Ayres et al., 2018; Hong et al., 2016). The move from objective to subjective QoL measures resulted in part from the change in focus from a medical model of disability to the biopsychosocial and social models of disability. Research with autistic individuals no longer focuses entirely on how to “fix the person” and make their outcomes the same as everyone else, thus comparing outcomes to nonautistic norms. Rather, research is beginning to focus on understanding the perspectives of autistic individuals and how environmental contexts impact on their ability to experience a good QoL (Ayres et al., 2018). Of course, this can be done effectively only when it is the individuals themselves who provide this information, hence the increase in self-reporting on QoL measures.

The outcomes of this contemporary research have shown considerable differences. It has been found that autistic individuals generally report a better QoL than their parents or others (Ayres et al., 2018; Clark et al., 2015; Hong et al., 2016; Sheldrick et al., 2012). Furthermore, there has also been shown to be greater levels of variability in ratings of QoL for autistic individuals; thus, individuals’ ratings of QoL relate specifically to their self-perceptions across the domains. In the Oakley et al. (2021) study, a notable proportion of autistic individuals rated their QoL as good. Although autistic self-reports show variability within the QoL domains, social participation is consistently shown to be the area where the most difficulties, and therefore the poorest QoL, are experienced (Clark et al., 2015; Lin & Huang, 2019), indicating that autistic individuals are aware of the various challenges that they face in a nonautistic society. The increased variability in ratings of QoL provides a more nuanced understanding of QoL, which is based on the values, expectations, and individual/environment fit for the autistic individual. This reinforces the importance of considering QoL "on an individual basis rather than assuming lower perceptions of QoL simply because of a diagnosis" (Clark et al., 2015, p. 61).

Furthermore, research on QoL in autistic individuals is beginning to show that QoL domains are influenced by both personal and environmental factors (Lombardi et al., 2019; Schalock, 2020). Van Heijst and Geurts (2015) and Clark et al. (2015) indicated that individual autistic characteristics, including IQ, age, communication, and behaviour differences, appear to have less of an impact on QoL ratings than the level of support that the individual experiences. This was supported by Lin and Huang (2019), who found that loneliness is a significant factor in how young adults rate their QoL. When considering this finding about the implications of environment for loneliness (see Section 2.5.4 Social Participation), it should not be viewed as being solely the result of the core autism characteristic of social communication differences, but equally because nonautistic people have difficulties understanding and socialising with autistic individuals (Kapp, 2018; Morrison et al., 2020; Sasson et al., 2017). Thereby, suggesting that this is, in fact, an environmental impact rather than an individual impact.

Renty and Roeyers (2006) suggested that the quality of support offered is more influential to the QoL of people on the autism spectrum than the characteristics of their disability. Similarly, Schalock and Verdugo (2002) and Erez and Gal (2020) emphasised the importance of environmental supports when measuring both the objective and the subjective QoL of an individual. For example, a young adult may be able to do things that they value with support that they would otherwise not be able to do. Thus, the support helps to improve their subjective QoL. From this perspective, it is suggested that there are currently no specific or validated comprehensive QoL measures for individuals on the autism spectrum. Because of this, most studies used QoL indicators that may not take into consideration the nuances or differences that are experienced by people on the autism spectrum, such as supports that are offered or different values. Thus, while autistic individuals may share universal QoL domains, specific indicators related to the characteristics of the individual that impact on QoL may also need to be considered (Ayres et al., 2018; Erez & Gal, 2020). In research conducted by Mattys et al. (2018), young autistic adults shared that "searching for balance between what can be expected from the young adult with ASD and what was possible" (p. 324) was the primary struggle faced during the transition to post-school options.

Given the focus on environmental supports, and findings that indicate that parents provide most of this support for those who need it (Cribb et al., 2019; Mattys et al., 2018), Clark et al. (2015) and Sheldrick et al. (2012) suggested that parent reports on QoL for their autistic child can be useful in painting a full picture of the experience of the individual and the family in which he or she lives. Although parent reports tend to provide similar or lower scores than the autistic individual reports themselves (Clark et al., 2015; Sheldrick et al., 2012), parent reports have been shown to align closely with the autistic individual's QoL ratings when asked to report as the individual's proxy. This includes reporting how they think that their child would report, rather than their own personal views on their child's QoL (Hong et al., 2016). This indicates high levels of understanding of their child's wellbeing, and while reflective of the different perspectives and reasoning of the parent, it shows that parental reports can provide supporting supplementary information (Clark et al., 2015).

2.6. Significance of the Research

Given the increasing numbers of autistic adolescents attending mainstream secondary schools and that adolescence is a vital transition period from childhood to adulthood, it would be expected that significant research would have been conducted on the specific needs of autistic people during this period of their life. Worryingly, this is not the case, with relatively little research having been conducted into the specific needs of adolescents or the supports and interventions needed to enhance QoL during this transition (Kapp, 2018; Keen et al., 2016; Kucharczyk et al., 2015; Pellicano et al., 2014).

The majority of international autism research conducted to date has focused on two main areas: the neurobiological basis of autism (Pellicano et al., 2014); and early intervention programs designed to support the autistic child's early development and transition into school (de Bruin, 2019; Kucharczyk et al., 2015; Pellicano et al., 2014). This would seem to reflect a continuing bias towards the importance of school participation, with little emphasis on the lifelong goals of education for the remaining 50 – 60 years of life post-school. While early intervention programs are shown to have positive effects on the initial acquisition of skills in young autistic children (Landa, 2018), it cannot be expected that the changing needs of individuals as they transition through adolescence and into adulthood can be met through early intervention alone. Rather, the importance of recognising the evolving needs of the individual at various stages of development, such as adolescence and young adulthood, is crucial when looking to develop an effective approach to lifelong support and intervention for young people on the autism spectrum (Howlin, 2021; Sosnowy et al., 2018).

The significance of this research addresses several unmet research needs. The first unmet research need is the importance of providing a voice for young people through opportunities to share their perceptions of the transition-focused practices in secondary schooling and of their current QoL (United Nations Convention on the Rights of Persons with Disabilities, 2006). Autistic individuals experience the world in a unique way; most research to date has focused on gathering data about autistic individuals' experiences through proxy reports, that is, through parents, teachers, and professionals who live and work with the autistic individual. More contemporary research has shown that people on the autism spectrum are able to share personal perceptions (Waldock, 2019), especially when this perception is based on subjective experience, or their own personal views on how they experience education, transition to post-school, and QoL as a young adult. Thus, providing them with the opportunity to share their perceptions is critical.

The second unmet research need is to explore the current transition practices of Queensland schools for autistic adolescents, where research has been limited (Beamish et al., 2012; Meadows et al., 2006). Specifically, there is no research on young Queensland adults' perceptions of this topic. As schools strive to improve practice to more effectively meet the needs of young people who experience disability (Queensland Government, 2021a), knowledge about how these practices impact on students is critical. Importantly, to meet the expectations of the Alice Springs (Mparntwe) Education Declaration (Education Council, 2019), further research is needed to understand the interaction between transition practices and post-school outcomes. There is a "paucity of qualitative research on how young people on the autism spectrum experience the stage of transitioning to adulthood themselves" (Mattys et al., 2018, p. 322) and this research study adds to the literature base.

Finally, research based within the biopsychosocial model of disability is needed. The changing focus from considering all disability to exist within the individual, to recognising disability as existing within the interactions between individuals and their environments is imperative. Research within this perspective can focus on the strengths of young people on the autism spectrum and build knowledge of how to create educational environments that allow them to thrive. Although schools are not solely responsible for young autistic adults' outcomes, the important role that they play cannot be denied. As a society, we need to strive for optimal educational practices that enable all our youth to reach their full potential.

2.7. Chapter Summary

Chapter 2 has presented a summary of the literature relevant to the transition of young autistic adults from school to post-school options. Within this literature a range of topics needed to be considered. The first was the concept of autism, what it is, how it is experienced, and how this concept has altered owing to a change in the model of disability that has been used to underpin research, policy, and practice. The influence of the experience of autism on educational outcomes was then discussed. Specifically, the complex interplay among academic, social, and emotional expectations and autism specific characteristics in educational contexts was shown. It was identified how young autistic individuals can struggle to achieve positive academic, social, and emotional outcomes during their secondary schooling experience.

Transition-focused education was explored, and it was suggested to be an evidence-based strategy for improving the academic, social, and emotional outcomes experienced by autistic students during their schooling. Importantly, it was also proposed that improving schooling outcomes, particularly with the TTP, could in turn improve post-school outcomes and QoL for young autistic adults. The poor post-school outcomes of young autistic adults were discussed, with a particular focus on the interaction between the individual and the environmental characteristics that supported these outcomes, indicating the key role that schooling experiences played in the success of young autistic adults gaining employment, attending postsecondary education, living independently, and experiencing positive social participation. Finally, the connection of each of these factors to the experience of QoL was presented, with a clear justification for the importance of secondary school transition practices in the experience of QoL as a young adult.

CHAPTER 3: CONCEPTUALISING THE STUDY

3.1. Chapter Overview

The conceptual framework of this study was developed by the researcher to show the links among the underpinning elements. A conceptual framework is defined as one designed to specify the key concepts being employed in a study and is used to demonstrate how those concepts are used to explore the phenomenon in question (Cohen et al., 2017). Thus, the conceptual framework for this research was used to support the purpose of the study, which was to share the views of young autistic adults who attended Queensland mainstream secondary schools about the interaction between school-based transition practices and post-school QoL. The conceptual framework was the underlying structure derived from the orientation of the researcher towards young autistic adults and their experiences as they transitioned from school to post-school options. That is, the structure of the study, the research questions posed, the methods chosen, and the sense made of the data collected were all equally influenced by the conceptual framework. The study therefore reflects the constructs, concepts, language, models, and theories that structured the study in the first place (Merriam & Tisdell, 2016).

The theory underpinning this study, self-determination theory (SDT), is used to conceptualise how and why the concepts presented were entwined, and how an understanding of the relationships among them helped to interpret and make sense of the information provided (Merriam & Tisdell, 2016). The analysis of the data was influenced by how the interaction between school-based transition practices and post-school QoL for young autistic adults is understood. With SDT being employed, the conceptualisation of the interaction between the individual, the autistic adolescent, the environment, and the secondary school, was key to understanding how and why transition practices in secondary school impact the post-school QoL of young autistic adults through the development of self-determination.

The understanding of autism, of how it is experienced by the individual and by those around them, and of the way that individuals on the autism spectrum experience the constructs of SDT are also explored and related to the conceptual framework. Although SDT has been empirically researched and is considered a universal theory (Ryan & Deci, 2017), the link between SDT and autistic individuals is still in the early stages of research. Thus, the discussion of the conceptual framework mobilised for this research investigates the links between autistic individuals and SDT, with particular reference to how this impacted on the findings of the study. Following this, the biopsychosocial model of disability and how its relationship to autistic individuals, their characteristics, and the ways in which the community responds to these characteristics, are considered. Specifically, the connections among SDT, autism, and the way that the environment is structured either to support or to hinder the development of SDT for the autistic individual within the biopsychosocial model of disability are discussed.

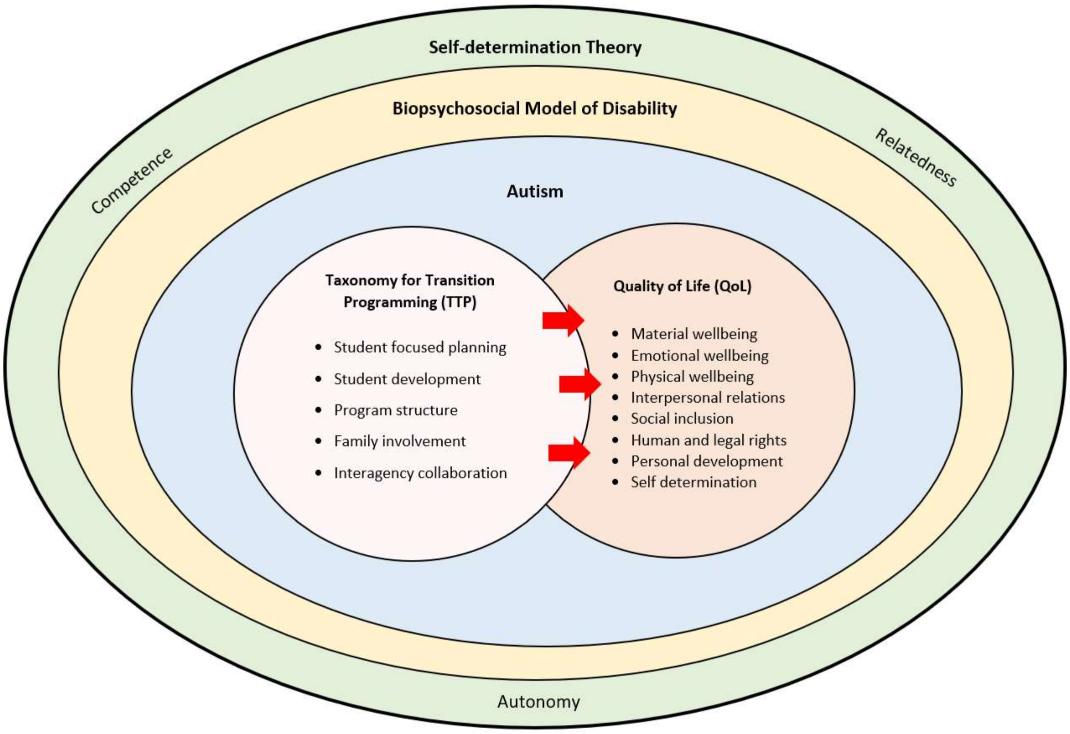
Finally, the two frameworks depicting best practice for transition practices, Taxonomy for Transition Programming (TTP) (Kohler, 1996), and understanding QoL in individuals with intellectual and developmental disabilities (Schalock & Verdugo, 2002), are discussed. Both frameworks were conceptualised as fitting underneath the umbrella of SDT for autistic individuals. That is, how the individual experiences both the school and post-school environments, and how these environments fit the characteristics of the autistic individual will either support or hinder the development of SDT for that individual. Specifically, the research addressed the perceived interconnection of these frameworks for young adults on the autism spectrum.

3.2. Conceptual Framework

The conceptual framework presented in this chapter was used to conceptualise ***how*** the concepts presented were entwined, and ***how*** an understanding of the relationships among them helped to interpret, infer, or make sense of the information provided through the study. It provided a "systematic view of phenomena by specifying relations among variables, with the purpose of explaining and predicting the phenomena" (Kerlinger, 1970, p. 9, cited in Cohen et al., 2017). It gathered together the nominated theories, concepts, models, terms and thoughts that underpin transition from school to post-school options for young adults with autism and it synthesised this understanding into a coherent conceptual framework. Figure 3.1 is a visual representation of the researcher's perception of how autism can be considered through the biopsychosocial model of disability under the umbrella of SDT. From this understanding the impact of transition practices could be assessed through the TTP and evaluated in terms of the impact that they had on post-school QoL. Within this conceptual framework, the red arrows represented the interconnections that were conceptualised as existing between these two frameworks. That is, how do young autistic adults perceive the interaction between Queensland secondary school transition practices and post-school QoL?

Figure 3.1

Conceptual Framework



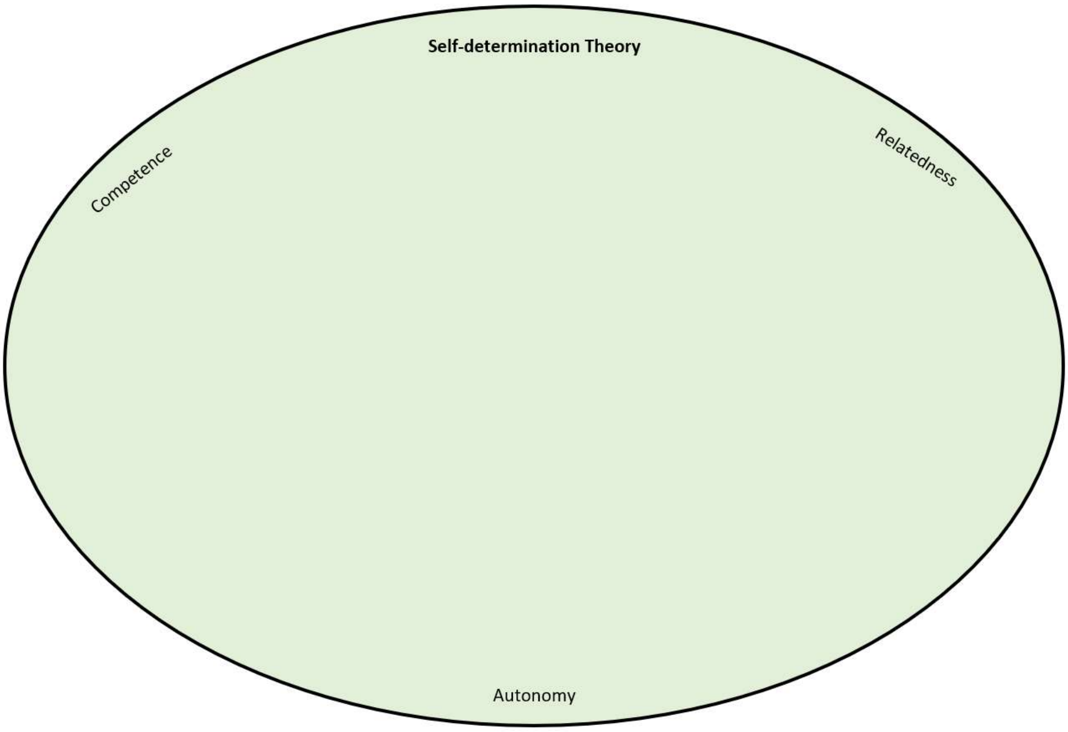
3.3. Self-determination Theory

SDT was the overarching, or umbrella, theory used within the conceptual framework developed for this study. There are many different interpretations, concepts, and definitions of the term ***theory*** (Cohen et al., 2017). How we define theory depends on what we want theory to do. For the purposes of this research, the interpretation of theory was that it is "an approach or 'paradigm' involving whole philosophies, in the sense of distinctive sets of ontological, epistemological, and perhaps also praxiological assumptions" (Hammersley, 2012, p. 393). From this perspective SDT was used as the tool that provided a structure and a language for considering the experience of transitioning from school to post-school for young people on the autism spectrum (Hammersley, 2012). Additionally, SDT is “based on and bounded by researchers’ assumptions about the subject matter in question” (Alvesson & Sandberg, 2013, p. 51). The use of SDT theory from my perspective as the researcher implied that I considered SDT to be as relevant to the QoL and wellbeing of people on the autism spectrum, as it is relevant to nonautistic individuals.

The use of theories in qualitative research studies can be contested, as qualitative research generally takes on an inductive approach to determining research findings (Cohen et al., 2017). That is, the research findings are built from the research participants’ perceptions of their experiences and from the interpretation of these experiences between the researcher and the participant. The use of an overarching theory in this research study was not intended to prove or to challenge the existing theory, but rather to analyse the perceptions of the research participants through the lens of SDT. In this way the research findings were interpreted in light of the beliefs underpinning SDT and have contributed to expanding the knowledge base of the theory (Merriam & Tisdell, 2016). Furthermore, Alvesson and Sandberg (2013) suggested that the use of a specific theory can challenge our taken-for-granted assumptions about a particular phenomenon. The use of SDT in this study challenged traditional societal and educational assumptions that autistic individuals are not capable of, nor require, self-determination. On the contrary, the lens of SDT theory was used to show how secondary school transition processes can either support or undermine the development of self-determination and positively or negatively influence post-school outcomes.

3.3.1. Overarching Theory

Figure 3.2
Conceptual Framework with Self-determination Theory



Ryan and Deci (2020) describe SDT as a comprehensive theory that has been developed from a "brick by brick" (p. 7) approach to theory construction that relied on decades of both quantitative and qualitative research methods. Figure 3.2 shows how SDT was seen within the conceptual framework as the beginning lens through which all data was considered. Through this construction, SDT has used empirical data to show the universality of human needs, while also supporting the unique individuality present in development. Furthermore, it is suggested that the general principles presented in SDT are both reliable and predictive of individual functioning across all social cultures and contexts, and across an individual's lifespan (Deci & Ryan, 2002; Ryan & Deci, 2017, 2020). This expansion of the basis of SDT theory to include different cultures, ages, characteristics, and contexts has occurred over many decades and has incrementally added various social contexts underneath its umbrella of understanding. Thus, SDT provides a unified perspective on diverse phenomena including those relating to education, transition, QoL, and young adulthood, and for people who experience disability such as those on the autism spectrum.

At its core, SDT is an overarching theory used to describe how individuals develop psychologically to become happy, healthy, functional adults who determine their own life outcomes (Ryan & Deci, 2000). The theory suggests that all individuals have a natural tendency to strive towards positive and continued development through greater autonomy and integration of the individual's values, emotions, experiences, and behaviours, and to develop greater connectedness with others. It is based on the premise that all organisms, including humans, "possess an inherent, active tendency toward the extension, progressive transformation, and integration of structures, functions and experiences" (Ryan & Deci, 2017, p. 29).

Importantly, while SDT allows the consideration of individual factors in a person's development, it simultaneously identifies and describes the contextual factors that influence this development. SDT states that both the individual and how the individual experiences their environment interacts either to support or to undermine healthy psychological functioning. Under SDT both individuals and their environments are considered critical players in psychological development and in the outcome of self-determination and wellbeing (Ryan & Deci, 2017). From this perspective the belief is that all people have basic psychological needs and that, when the interaction between individuals and their environments allows those needs to be fulfilled, effective functioning and positive wellbeing are the result. Conversely, when the individual's needs are not fulfilled, negative wellbeing and difficulties with self-determined functioning will occur (Ryan & Deci, 2020).

3.3.2. Basic Psychological Needs

Basic psychological needs are those needs that are a requirement for all individuals to achieve positive wellbeing and functioning (Ryan & Deci, 2020). To be considered a basic psychological need, Ryan and Deci (2017) suggested that need satisfaction must result in observable and meaningful positive consequences for wellbeing and functioning, and that deprivation of these needs should result in significant harm. Furthermore, these needs should be relevant across every domain of development, and at all ages across the lifespan. SDT theorises that there are three basic psychological needs that meet these requirements: autonomy, competence, and relatedness (Ryan & Deci, 2017).

An important understanding of basic psychological needs is that they "reflect our adaptive human design and are therefore universal" (Ryan & Deci, 2017, p. 88). While it is beyond the scope of this review of SDT to provide a detailed discussion of the evidence provided to support the identification of these basic psychological needs, Ryan and Deci (2017) provided significant evidence of the universality of their three basic needs as a constant, unchangeable aspect of human makeup that applies to all humans in all cultures and in all contexts. Thus, part of SDT's premise is that the functional benefits of need exist across varied cultural and social contexts, and, it was argued in this research study, those benefits include the social context of the experience of autism.

This claim that the three basic needs are inherent and universal features of positive human functioning does not assume that all individuals or groups will equally recognise and value these needs, nor does it suggest that all individuals are equally equipped to achieve need fulfilment or that all environments support need fulfilment (Ryan & Deci, 2017). Rather, SDT acknowledges the complex interactions between individuals and their environment as they struggle to fulfil their basic psychological needs of autonomy, competence, and relatedness (Sheldon & Prentice, 2019). From this perspective, it is suggested that optimal functioning for individuals requires structures and supports within the environment to help the individual to achieve those three basic needs.

3.3.3. Autonomy

Autonomy, the first and often the most contentious of the posited basic psychological needs, refers to individuals feeling willingness and volition with respect to their own behaviours (Ryan & Deci, 2017). From the beginning of SDT, the need for individuals to feel a sense of initiative and ownership over their own actions has been perceived as critical to achieving self-determination and positive wellbeing. It is argued that, when individuals make decisions for themselves and feel that these decisions are consistent with their own needs, values, and goals, positive wellbeing and self-determination will result. Conversely, when individuals feel that their behaviours are controlled or influenced by outside forces that do not align with their needs, values, and goals, they will experience negative wellbeing and their self-determination will be undermined (Deci & Ryan, 1985, 2008; Ryan & Deci, 2017).

An important understanding within SDT is that autonomy does not equate with independence. Independence as defined by Merriam-Webster (2022) is "freedom from outside control or support", whereas autonomy is defined as "an expression of the self, such that, even when actions are influenced by outside sources, the actors concur with those influences, feeling both initiative and value with regard to them" (Deci & Ryan, 2002, p. 8). Therefore, independence does not imply autonomy; rather, it implies being either separate from and/or not reliant on others (Ryan & Deci, 2017). Autonomy refers to feelings of self-regulation, self-endorsement, and ownership of actions, even if those actions involve choosing to be dependent on others, accepting support from others, or being interdependent with others. With this understanding of SDT, autonomy, independence, dependence, and interdependence can each be experienced autonomously depending on the context and the underlying values of the individual. Moreover, being self-reliant and separated from others does not imply autonomy as this may occur without volitional choice by the individual. Understanding the differences between these two terms, ***autonomy*** and ***independence***, is critical to the understanding of SDT and the universality of autonomy as a basic psychological need.

Within this understanding of autonomy, there have been many studies that have shown 'autonomy as volition' to be relevant across cultures, gender, age, socio-economic status, and different contexts (Deci & Ryan, 2002, 2008; Ryan & Deci, 2017, 2020). While there have been fewer studies relating to SDT, autonomy, and the experience of disability, this point is critical to understanding the relationship between SDT and disability, and how the concepts of SDT and autonomy were used in this study.

Western cultures, such as Australia, tend to emphasise individuality, uniqueness, and independence as being necessary to achieve self-determination (Nalipay et al., 2020). With this emphasis, individuals are seen as being autonomous and achieving self-determination only when they can function completely independently from all others. For people on the autism spectrum, many of whom require additional support across their lifespan, this implies that they will never achieve autonomy or self-determination. This perception, however, does not align with the core elements of SDT (Ryan & Deci, 2017). Rather, self-determination will be achieved when individuals feel a sense of self-endorsement for the support that they receive to achieve their goals. For people on the autism spectrum who may require additional support to achieve the goals of self-care, employment, or living in their own home, volitionally accepting this support equates to experiencing autonomy. In fact, from this perspective it could be argued that self-determination and autonomy may occur only when individuals are provided with the interdependence and support required to allow them to achieve their values and goals. It is important to note that this concept does not apply only to people on the autism spectrum or to people with disability, but rather to all people, and hence autonomy is considered a universal need. Few, if any, individuals are able to function completely independently from all others throughout their lifespan, and, more importantly, few would ever want to do so.

Within this study, acknowledging that the development of autonomy does not require independence is an important understanding for how SDT was used as the umbrella under which all other concepts were considered. As adolescents move into young adulthood and transition from school to post-school options, they do need to gain a sense of themselves as self-regulating individuals with capacities for autonomy; however, they do not need to separate or detach themselves and their actions completely from their parents or other support structures. Rather, developing autonomy as a young adult requires that parents and others increasingly support the young person to take responsibility for himself or herself and engage in reflective choices (Ryan & Deci, 2017). In other words, what is needed is an environment that supports the young people’s need for both autonomy and support as they move through the transition from school to post-school, and from adolescence to adulthood. Furthermore, it is argued in this research that young adults are more likely to become autonomous adults when they are provided with appropriate support by their parents, schools, and support agencies throughout this transition process (Taylor et al., 2019).

Because it is through volitional action that people access and fulfil their basic needs, autonomy has a special status as a need (Ryan et al., 2006). It is the vehicle through which the other basic psychological needs are actualised. For example, individuals will more readily internalise a sense of competence when they succeed at an activity that they have initiated or willingly undertaken. Similarly, people have the experience of relatedness when others willingly care for them, and they are willingly connected with and caring for the other (Ryan & Deci, 2017). In other words, the full satisfaction of the basic needs for competence and relatedness is enhanced when autonomy or volition of action is also satisfied.

3.3.4. Competence

Competence as a basic psychological need concerns the feeling of mastery and a sense that one can succeed and grow in the areas that they consider important. It is defined by Ryan and Deci (2017) as "feeling effective in one's interactions with the social environment, that is, experiencing opportunities and supports for the exercise, expansion, and expression of one's capacities and talents" (p. 57). The need for competence is best satisfied within well-structured environments that afford optimal challenges, positive feedback, and opportunities for growth (Ryan & Deci, 2017). The experience of competence is closely connected to the environment, as it is through influencing the environment that one develops a sense of competence.

As a psychological need, competence is not only functionally important but also experientially important. Achieving feelings of effectiveness not only increases individuals' overall sense of self-efficacy, or their belief that they can have a positive impact on their own lives, but also allows those individuals to function in the way that they choose on a day-to-day basis. Hence, both the intrinsic and the functional importance of competence need to be considered together. It is not just the skill learned and its potential value that are important, but also the inherent belief that skills can be learned, and that the environment can be changed, that makes achieving competence, in whatever form, valuable to self-determination (Ryan & Deci, 2017). Conversely, feelings of being ineffective threaten individuals' competence and undermine their motivation for action. If those individuals do not have the skills or are not able to learn the skills needed to meet their values and goals, the need for competence is not met and the opportunities for self-determination are reduced (Deci & Ryan, 2008; Ryan & Deci, 2017).

Although the activities and skills that an individual needs to be competent change across the lifespan, the need for competence remains intact. In this way, achieving competence for age related skills and activities is an important aspect of growth and development. Furthermore, where individuals are prevented from developing skills, understanding, or mastery, the competence need will be unmet, and this in turn will impact on motivation and development (Ryan & Deci, 2017). Similarly, being unable to master the competence required at different stages of development will slow down developmental progress and may impact on the individual's perception of competence. For people who experience disability, including those on the autism spectrum, achieving culturally valued competence can be problematic.

Across different cultures, competence is typically viewed within narrow constructs. That is, the understanding and mastery of a narrow set of skills are deemed important to achieve competence. In Western cultures, competence skills can be narrowly defined as cognitive or academic achievement during the school years, and strongly focused on employment, independent living, and financial skills in adulthood (Arnett, 2014). For autistic individuals, who may possess a different set of skills from those that are valued in the school or employment sectors, recognition of competence can be very hard to achieve. Ryan and Deci (2017) stated that people typically gravitate towards practices and value systems within which they can achieve competence and they fail to be motivated and autonomous in relation to those that are beyond their understanding or capacities. Thus, the fit between an individual's perceptions of competence and the expectation of the environment is paramount for achieving self-determination.

These are important concepts when applied to the transition from adolescence to adulthood for young autistic adults. The skills and understanding required in the transition across these two stages of life are very different, and that this period of transition is one where a significant increase in the complexity of skills required will impact on perceived competence and autonomy in the various skill domains (Deci & Ryan, 1985). Thus, transition practices used to support the young adults as they transition from school to post-school options become critically important, as it is from these practices that the young adults will develop competence, and in turn autonomy, across the new context of adulthood.

3.3.5. Relatedness

The third and final basic psychological need, as described by Deci and Ryan (1985) is that of relatedness. Relatedness refers to having a sense of belonging and connection to others within the environment and is described as "experiencing others as responsive and sensitive and being able to be responsive and sensitive to them, that is, feeling connected and involved with others and having a sense of belonging" (Ryan & Deci, 2017, p. 93). Relatedness is experienced both in being cared about and in caring. This need is satisfied when others show respect and caring towards an individual, and that individual has opportunities to show respect and caring towards others with the bidirectional nature of caring enhancing the sense of connectedness and relatedness (Ryan & Deci, 2020).

It was suggested by Ryan and Deci (2017) that one of the primary goals of any behaviour is to feel a sense of belonging and connection with others. It must be recognised that for human beings who are social and cultural creatures, few such events take place outside social contexts and interpersonal relationships. Almost all experiences that occur in a person's life occur with another person or group of people whose relationship with and response to the individual, shape how these events will be interpreted (Ryan & Deci, 2017). There is a basic need to feel responded to, respected, and important to others. Conversely, there is a basic need to avoid rejection and disconnectedness. SDT posits that this fact applies to all humans, regardless of their social context (Ryan & Deci, 2017).

As a basic psychological need, relatedness can be either facilitated or undermined. Facilitation of relatedness means that the environment and interpersonal relationships within this environment support need satisfaction, whereas undermining relatedness means that the environment and relationships within the environment thwart need satisfaction. For example, an individual who is treated with respect and consideration by others in the environment will experience a sense of relatedness, while an individual treated with disrespect and rejection will not. The mere presence of others in the environment is not enough to achieve relatedness. In this way, the basic psychological need of relatedness is closely tied to the environment and to the behaviour of others.

An important issue associated with SDT concerns the differentiation between behaviours intended to achieve relatedness and those that actually satisfy this basic psychological need (Ryan & Deci, 2017). People can behave in ways that they think that others would like, in order to feel connected to those others, but, unless those people feel somehow personally acknowledged and affirmed for their actions, the relatedness need will not be fulfilled (Ryan & Deci, 2017, 2020). That is, people within the relationship need to care for each other autonomously for the need for relatedness to be achieved. "It is a fundamental tenet of SDT that autonomy and relatedness satisfactions are not antithetical but, rather, are intricately connected with one another. Indeed, the fulfillment of each need is intertwined with the fulfillment of the other" (Ryan & Deci, 2017, p. 293).

This understanding is critical for autistic individuals as their different experiences of social and interpersonal contexts are a core part of their experience of autism. Their experience of social contexts and relatedness is based upon an understanding of social situations that varies significantly from the experience of others, and, as a result, is often interpreted very differently by both the autistic individual and the nonautistic individual with whom they share social experiences. From this perspective, it can easily be seen how the experience of relatedness can be very difficult for some autistic individuals to achieve. In fact, the conception of relatedness for the autistic individual living in a nonautistic world can be seriously hindered through lack of understanding of the autistic experience (Williams, 2018).

Despite this difference of experience for autistic individuals, SDT suggests that, whether an individual has an explicit awareness of this need or not, and whether environments provide supportive relationship experiences or not, all people have an ongoing need to experience relatedness (Ryan & Deci, 2020). At the same time, the effective functioning of societies requires individuals to adapt to social expectations and to coordinate their social behaviours so that groups can function. Typically, there is a natural readiness on the part of individuals to take on the social expectations that are valued by groups to whom they are attached, as doing so means that individuals can satisfy their basic psychological needs of autonomy, competence and relatedness (Ryan & Deci, 2017). However, for autistic individuals, these nonautistic social expectations can be very difficult to understand and self-endorse as they are so different from the social experience of autistic people. This can have significant negative impacts on the sense of belonging and wellness that autistic people experience. Thus, for people on the autism spectrum, differences in social communication, and the behaviours used to regulate these social experiences can result in fundamental differences in the level of self-determination experienced.

Relatedness for many autistic individuals, often refers to the relationships with those who have a fundamental and basically positive understanding of the individual's experience of autism. Parents, families, and close friends and partners are often the people who have this understanding, as they spend the most time with the autistic individual and see the mismatch between the young autistic adults' needs for autonomy, competence, and relatedness and the expectations of the social environments in which they live.

3.3.6. The Importance of all Three Basic Psychological Needs

One of the most important aspects of SDT's basic psychological needs is that the satisfaction of all three needs is deemed essential for a person to be fully functioning. Each need is independently important, and deprivation of any is seen as problematic (Ryan & Deci, 2017). Thus, for individuals who have high levels of self-determination and wellbeing, all three needs will tend to be satisfied. In addition, SDT posits that all three basic psychological needs are interdependent; that is, each need facilitates the satisfaction of the others under most conditions (Deci & Ryan, 2008). For example, high levels of autonomy support the satisfaction of competence and relatedness needs. Similarly, high levels of relatedness support the satisfaction of autonomy and competence, and so on.

Additionally, it has also been suggested that the fulfilment of all needs should be consistent across the lifespan for optimal development. Sheldon and Niemiec (2006) found not only that the three basic needs should be met, but also that balance in the satisfaction of the three basic psychological needs is also important for overall wellbeing. Across their research, it was shown that individuals who experienced more balanced need satisfaction reported higher levels of wellbeing than those with the same summary score of need satisfaction but who reported greater variability among the three needs in their levels of need satisfaction. Milyavskaya et al. (2009) also examined need satisfaction balance across the lifespan and found that unbalanced need satisfaction across important life domains had an additional negative effect on wellbeing. This suggested that any uneven needs satisfaction experienced in important life domains results in more negative wellbeing and reduced self-determination across the lifespan. This understanding was particularly relevant to the current study as it examined the perceptions of young autistic adults on their QoL, and the impact school transition practices had on this QoL as they transitioned from school to post-school options. The period of transition from school to post-school is identified as a key period that can either enable or disable positive future outcomes as an adult (Arnett, 2014). SDT suggests that consistently high levels of need satisfaction in autonomy, competence, and relatedness, across this transition period will result in optimal self-determination and wellbeing during adulthood.

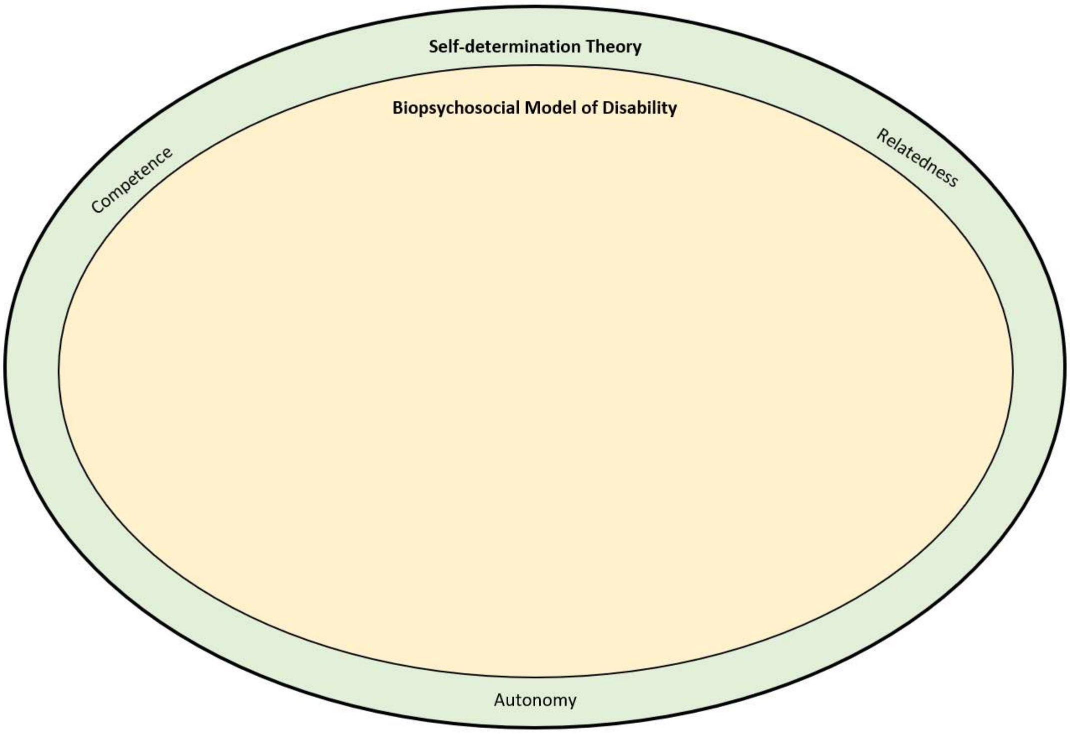
By contrast, if the fulfilment of any of the three basic psychological needs is blocked within a given domain or in a given period in an individual's life, negative outcomes in self-determination and wellbeing can be expected. Need deprivation of any basic need, in any life domain or context, will incrementally diminish self-determination and wellbeing for the individual. Notably, the satisfaction of the need for relatedness is a "direct and independent predictor of psychological wellness, even controlling for other basic need satisfactions" (Ryan & Deci, 2017, p. 297). Failure to achieve relatedness is universally connected to psychological distress and ill-being. This is particularly relevant when it is not just an absence of relatedness but also the active thwarting of relatedness through exclusion, bullying, and/or abuse (Ryan & Deci, 2017). Thus, while an individual may achieve high levels of self-determination, or volition of action, through autonomy and competence, associated psychological wellbeing can be achieved only when relatedness is also achieved. Given the negative psychological wellbeing outcomes reported across the literature (van Heijst & Geurts, 2015) for autistic individuals, the satisfaction of the need for relatedness, and its connection with autonomy and competence are a key area of focus.

From this discussion, it can be seen that the relationship between autonomy, competence, and relatedness is complex and multi-directional (Deci & Ryan, 1985, 2008). It can also be seen how research over the decades has made it increasingly clear that, when need-supportive environments are not provided, the negative effects on development and wellbeing can be significant (Ryan & Deci, 2017). In fact, SDT specifically looks at the development of negative self-determination and wellbeing in terms of the environmental factors that have negatively impacted on the autonomy, competence, and relatedness of the individual (Ryan & Deci, 2020). Furthermore, SDT can be used to show how any individual vulnerability in the form of an impairment of difference, such as autism, can seriously impact on the achievement of self-determination and wellbeing across the lifespan as a result of environmental impacts.

3.4. The Biopsychosocial Model of Disability

Figure 3.3

Conceptual Framework with the Biopsychosocial Model of Disability



What disability is, and the way that it manifests, are typically an assumed knowledge that most people within a community share. In this conceptual framework, the biopsychosocial model of disability was viewed as critical to the understanding, within SDT, that it is the combination of individual and environmental factors that contribute to the experience of self-determination. Figure 3.3. depicts how the biopsychosocial model of disability sits within the overarching theory of SDT. In the traditional medical model of disability, the view of disability relates specifically to the impairment experienced by the individual, such as the person with down syndrome, cerebral palsy, or autism. The assumption is that the disability exists within the person, and that it is the person who needs to learn to function within the expectations of society (Pellicano et al., 2014). For example, the young autistic individual who struggles to initiate social interactions in the school environment will be provided with lessons on how to initiate social contact. When the young person then tries to initiate social contact using the skills taught, and the contact is ignored or ridiculed by peers, the issue is still seen to exist within the individual with autism, rather than working on the social skills of the peers to teach them how to recognise and accept initiated social contact by the individual. Thus, the person-centred view of disability puts the onus of research and practice on remediating the impairments within the individual with little consideration as to the impact of the environment.

Alternatively, the biopsychosocial model of disability (International Classification of Functioning Disability and Health [ICF], 2002) recommends a conceptual understanding of disability as encompassing the impairment and/or the differences experienced by the individual with a disability label, while at the same time recognising the activity limitations and participation restrictions based on the environmental response to the individual. Thus, the biopsychosocial and medical models of disability configure the relationship between disability and impairment differently (Graham et al., 2020). The medical model focuses on the impairment experienced by the individual, while the biopsychosocial model describes the experience of the individual and her or his personal characteristics, including the physical and mental health conditions, and the way that the environment impacts on the experiences and development of the individual.

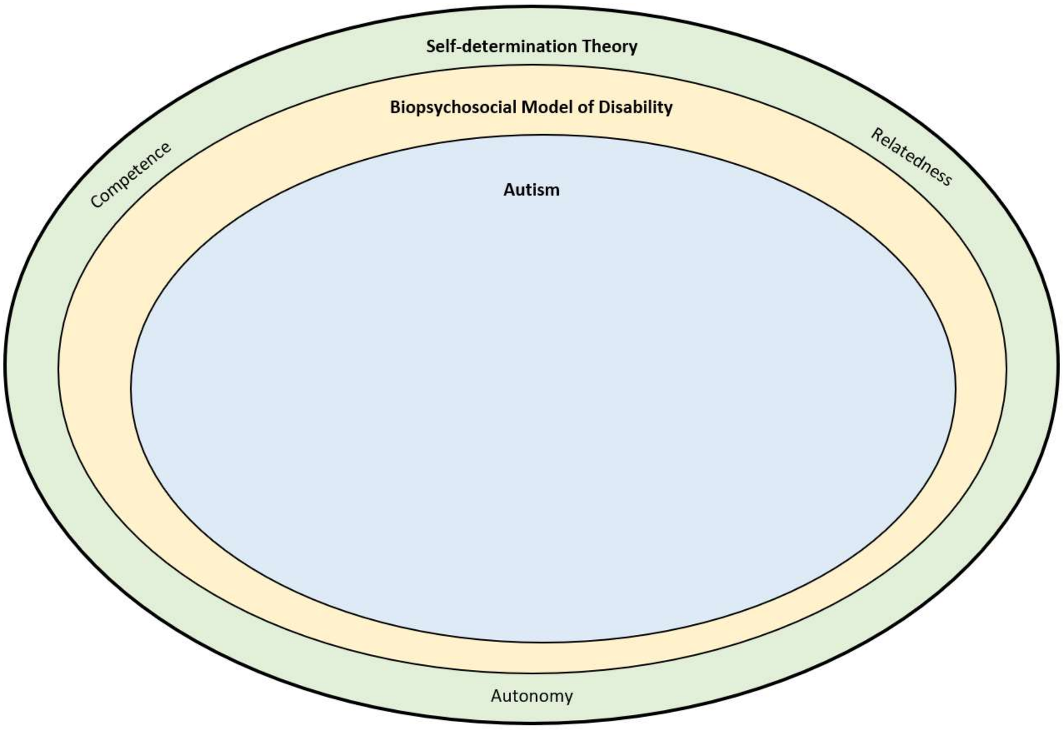
For this research, under the umbrella of SDT, the biopsychosocial model of disability is a more appropriate lens through which autism can be considered. From this perspective, the functioning of the autistic individual is considered not only from the perspective of the differences and difficulties that they experience because of autism, but also from the strengths that they possess and the way in which environmental factors influence the enabling or hindering of strengths and needs. Importantly, the biopsychosocial model of disability does not discount the differences in experience of autistic individuals, as to do so would risk discounting the uniqueness of the autistic experience, and not providing the support that many need to reach self-determination. It does not, however, see this experience as relying solely on the characteristics of the individual, but rather on the interplay between these characteristics and the environments in which the individual lives.

While research has supported these basic psychological needs across different cultures, genders, ages, and social demographics (Ryan & Deci, 2017), the conception of SDT within the social context of disability, and specifically within autism, is in its infancy. SDT looks at environmental factors and how they support or thwart the basic psychological needs of autonomy, competence and relatedness (Ryan & Deci, 2017). This evaluation occurs across both micro-environments such as families, schools and workplaces and macro-environments such as cultural and societal expectations, policies, and practices (Ryan & Deci, 2020). Therefore, it is proposed that SDT is an appropriate umbrella under which the biopsychosocial model of disability can be applied to analyse how transition practices of secondary schools are perceived by young autistic adults to impact on their QoL.

3.5. Autism

Figure 3.4

Conceptual Framework with Autism



Self-determination is considered a universal construct that applies to all people regardless of culture, gender, age, socio-economic status, or context (Ryan & Deci, 2017, 2020). Because of this, the assumption of this research was that self-determination is equally applicable to young autistic adults as they transition from school to post-school options. Figure 3.4 visually represented the views of the researcher that the experience of self-determination for individuals on the autism spectrum were considered within the viewpoints of SDT and the biopsychosocial model of disability. Specifically, the potential differences between how young autistic adults experience and demonstrate self-determination, including autonomy, competence, and relatedness were addressed, while acknowledging the different experiences of autistic individuals and how environments respond to these differences. Therefore, considering both personal and environmental characteristics that impact on the development and expression of self-determination for young autistic adults was a key deliberation in this research.

Importantly, it is necessary to point out the dearth of research regarding the self-determination of young people on the autism spectrum (Chou, Wehmeyer, Palmer, et al., 2017; Hagiwara et al., 2020). Most of the research concerning self-determination relates to the broad categories of students with special educational needs, students with intellectual disability (ID), or students with intellectual and developmental disabilities (IDD) (including autism). Research within these broad groups has shown that promoting self-determination provides benefits across outcomes in both school and post-school contexts for students with disability, and that promoting self-determination during school provides post-school benefits for young people with disability (Chou, Wehmeyer, Shogren, et al., 2017; Wehmeyer et al., 2013). Shogren et al. (2015) investigated adult outcomes, such as employment, community access, financial independence, independent living, and life satisfaction, at one and two years after leaving school. Results indicated that self-determination measured at the end of secondary school was causally related to significantly more positive employment, career goals, and community access outcomes. Despite these findings, Qian et al. (2020) found that students on the autism spectrum had some of the lowest levels of self-determination of all students with disabilities. Given this, it is difficult to know whether these findings were applicable to students on the autism spectrum or not. Furthermore, research relating to self-determination has focused primarily on students with disability in secondary school contexts. Considering self-determination for adults with developmental disabilities, such as those with autism, has not received significant attention (Hagiwara et al., 2020).

3.5.1. Outcomes of Self-determination for Autistic Individuals

Of the few studies conducted, findings suggest that young autistic adults experience low levels of self-determination compared to young adults with other disabilities (Cheak-Zamora et al., 2020). This is in line with research conducted by Mumbardo-Adam et al. (2017) that indicated that individuals within the broader category of IDD tend to report lower levels of self-determination than do their peers without disabilities. Furthermore, there is a consistent association between an individual's autism diagnosis and lower self-determination scores compared to other diagnoses even after controlling for ID and other individual and environmental factors (Mumbardo-Adam et al., 2017). These findings for young autistic adults are similar to the results for young autistic adolescents, with Qian et al. (2020) finding that secondary students on the autism spectrum showed lower self-determination scores compared than those of other disability groups.

When interpreting these findings, it is important to acknowledge that the research was typically conducted through parent reports rather than self-reports by autistic adolescents or adults (Cheak-Zamora et al., 2020). Moreover, the research relating to self-determination typically occurs through the American Institutes for Research (AIR) Self-Determination measure (Chou, Wehmeyer, Shogren, et al., 2017) or the Self-Determination Inventory – Student Report (SDI-SR) (Shogren et al., 2020). Both measures were developed and are used primarily for determining self-determination in young people with disability. Thus, it calls into question whether the unique characteristics associated with autism and the way that self-determination is demonstrated in this population is adequately assessed through quantitative, proxy-report measures (Cheak-Zamora et al., 2020; Spath & Jongsma, 2020).

Regardless of these potential difficulties in measuring self-determination in autistic individuals, it is widely accepted that the process of developing self-determination and benefiting from it into adulthood is reduced in individuals on the autism spectrum. Chou et al. (2017) suggested that it may be the key characteristics of autism, social communication differences, and restricted and repetitive behaviours and interests that may undermine self-determination in this population. Alternatively, Cheak-Zamora et al. (2020), Hagiwara et al. (2020) and Moran et al. (2021) all suggested that it is in fact a complex interplay between personal and environmental factors that result in low levels of self-determination in the autistic population. Hagiwara et al. (2020) noted that “many contextual factors can be strong indicators of how people develop and express self-determination and how people perceive their own and others’ self-determination” (p. 401).

3.5.2. Personal Characteristics of Autistic Individuals that Impact Self-determination

A range of personal characteristics is suggested to impact on the attainment of overall self-determination for people on the autism spectrum, as they do for all other people. For example, age was found to be a significant predictor of self-determination for older students with disability showing higher levels of self-determination (Shogren et al., 2013). Hagiwara et al. (2020) replicated this finding, showing that generally older adults with and without disabilities scored higher on self-determination scores than did younger adults. However, gender was shown to play little role in overall levels of self-determination for people with disability, with both males and females showing similar levels of self-determination once age and disability category were considered (Cheak-Zamora et al., 2020).

Factors related to autism specific characteristics have also been shown to play a role in overall self-determination. Autism specific characteristics such as social skills and level of communication, were identified as influencing self-determination (Moran et al., 2021; White et al., 2018). Similarly, difficulties in self-determination are thought to result from the autistic individual’s preference for routine and sameness, as this reduces opportunities for exposure to situations encouraging this trait. Executive functioning and adaptive behaviour skills were also suggested by Cheak-Zamora et al. (2020) as impacting on overall self-determination, with a co-occurring ID also found to be associated with poorer levels of self-determination (Mumbardo-Adam et al., 2017), although as discussed previously this association is not consistent. Overall, studies have found that a range of individual factors, both general and autism specific, can influence the development and use of self-determination with autism specific factors appearing to have the largest impact. These autism specific factors are now considered against the three basic psychological needs of autonomy, competence, and relatedness.

Autism and Autonomy. Results across several studies indicated that students on the autism spectrum had significantly lower levels of autonomy compared with students with other disabilities and students without disability. For example, Chou et al. (2017) found that autistic students had lower levels of autonomy compared to both students with ID and students with learning disabilities (LD). These findings were further elaborated to show that autistic students had significantly lower levels of self-regulation, psychological empowerment, and self-realisation, all considered to be key features of self-determination (Wehmeyer et al., 2013). These findings are important in terms of self-determination for young adults, as Shogren et al. (2017) showed in their examination of the National Longitudinal Transition Study-2 data set that autonomy, psychological empowerment, and self-realisation play a mediating role in the relationship between school-based factors and post-school outcomes. That is, students with higher levels of these characteristics of self-determination experience significantly more positive post-school outcomes in adulthood.

It was proposed that these characteristics play a key role in developing the skills that support and lead to autonomy. Skills such as problem solving, goal setting, choice making, and decision making come into play to contribute to both greater autonomy and enhanced self-determination (Chou, Wehmeyer, Shogren, et al., 2017). For young people to know which goal they want to achieve, and to be able to make, execute, and monitor a plan to achieve that goal, is critical for achieving autonomy, and enhancing self-determination. Young people on the autism spectrum often experience difficulties with goal setting and planning because of underlying executive functioning difficulties (Cheak-Zamora et al., 2020). Thus, the connection between lower levels of autonomy and self-determination can be established.

Autism and Competence. As with autism and autonomy, the connection between lower levels of competence and self-determination can also be established for many people on the autism spectrum. As discussed in Section 3.3.4, competence is typically viewed within specific constructs depending on the context and anyone who deviates from this specific skill set may not be considered to have met the expected level of competence. In Australian society this often refers to a narrow range of academic skills in school and, for adults, to employment, financial, and independent living skills.

Many individuals on the autism spectrum experience difficulties in skill areas that are valuable for self-determination. As discussed above, self-regulation, goal setting, planning, and monitoring are all skills needed to engage competently across life domains. Adaptive functioning, including daily living skills, are also key skills needed to experience competence on an everyday basis. The abilities to engage in self-care, plan for and prepare meals, and manage a budget to cover expenses are all needed to experience everyday competence as a self-determined adult, and are also areas where young adults on the autism spectrum have been shown to experience difficulties (Ghanouni et al., 2021). Tomaszewski et al. (2020) demonstrated a strong relationship between adaptive behaviour and self-determination in secondary school students on the autism spectrum, indicating that autistic adolescents with higher levels of adaptive skills experienced higher levels of self-determination. Similarly, higher levels of adaptive skills are associated with positive outcomes in adulthood in employment and in independent living for young autistic adults (Smith et al., 2012).

Although individuals on the autism spectrum do show high levels of competence and skill, these are often very specific to their focused interests (Grove et al., 2018). Furthermore, these interest areas are often not valued by society, certainly not to the level of detail that the autistic person shows competence. These focused interests are related to the core characteristic of restricted and repetitive routines, interests, and activities (American Psychiatric Association, 2013), and, as a key characteristic of autism, they can impact on the individual’s ability to focus outside these interests (Waisman-Nitzan et al., 2020). In turn, this can impact on the interest in, and demonstration of, competence across a broad range of domains as required for self-determination.

Autism and Relatedness. Experiences of relatedness and its impact on self-determination for autistic individuals can also be considered through the core characteristics of differences in social communication (American Psychiatric

Association, 2013). As established in Section 2.5.4, individuals on the autism spectrum consistently experience social participation difficulties, including difficulties with initiating and maintaining the close reciprocal relationships that are necessary to experience relatedness (Mattys et al., 2018; Orsmond et al., 2013). Chou et al. (2017) share that “self-determination always has a social context” (p. 125), in that self-determination relates to the actions of individuals in relation to themselves and others. Therefore, they argued that social communication differences for young people on the autism spectrum may significantly affect self-determination for this population. Similarly, Tomaszewski et al. (2020) demonstrated support for the relationship between social skills and self-determination for adolescents on the autism spectrum from the perspectives of educators and parents, although this is not yet supported for self-perceptions of young people on the autism spectrum. Additionally, Huggins et al. (2021) found that emotional self-awareness is reduced in autistic adolescents and adults, which has been implicated as a key characteristic of both relatedness and autonomy (Wehmeyer et al., 2013). Furthermore, Huggins et al. (2021) showed that these differences in self-awareness tend to emerge in adolescence and continue to decline into adulthood, thus suggesting that difficulties with relatedness and autonomy could in fact decline throughout the transition from school to post-school options.

Although each of these personal characteristics has been shown to have significant impacts on the development of self-determination, Shogren (2018) suggested that these differences should not be “simply interpreted as differences in personal capacity per se but instead differences shaped by limited opportunities and supports” (p. 23). White et al. (2018) and Moran et al. (2021) also noted that, while several characteristics of individuals on the autism spectrum may impact on the development of self-determination, there is clear evidence that these individuals can develop self-determination skills and abilities when provided with appropriate environmental supports and accommodations.

3.5.3. Environmental Factors that Impact Self-determination for Autistic Individuals

More contemporary studies indicate that specific environmental factors also impact overall self-determination for adults with intellectual and developmental disabilities, including those on the autism spectrum. Importantly, it has been suggested that it is actually the limited opportunities autistic individuals have to express their autonomy, competence, and relatedness that result in poorer self-determination (Spath & Jongsma, 2020). Taylor et al. (2019) contended that socioecological environments can either support or thwart the fulfilment of the need for autonomy, competency, and relatedness, and in turn impact on the unified sense of self necessary for overall self-determination.

Qian et al. (2020) analysed data from the recent National Longitudinal Transition Study with findings confirming the important role that contextual factors, both personal and environmental, play in the development of self-determination for students with disabilities, including those on the autism spectrum. The environmental factors shown to have significant impact on self-determination for individuals, regardless of disability or age, were the expectations and support available at home, at school and in the community. Shogren et al. (2018), studied the factors affecting self-determination in students with disability, finding that socio-economic status has a significant impact on self-determination scores. These findings highlighted the importance that systems-level interventions and the impact of systemic barriers can have on self-determination for individuals, even when accounting for race, age, and disability, thus, showing that it is not only micro-level environments, such as family and school, but also macro-level environments at a societal and cultural level, that impact on self-determination for individuals with disability.

Hagiwara et al. (2020) conducted research specifically on the environmental influences of self-determination for adults with intellectual and developmental disabilities. Findings indicated that employment status and living arrangements had significant impacts on levels of self-determination. Adults with full-time employment had significantly higher overall self-determination than those who worked part-time or did not work at all. Likewise, adults who lived in their own home had significantly higher levels of self-determination than those who lived with their families or who lived in a group living arrangement. These findings would seem to indicate the cyclical nature of developing and demonstrating self-determination for adults with a disability (Hagiwara et al., 2020; Moran et al., 2021). That is, those individuals who have higher levels of self-determination are more likely to experience situations, such as employment and independent living, that further increase their self-determination, while those individuals who have lower levels of self-determination are less likely to experience situations that increase this trait.

These findings are significant as Shogren et al. (2015) and Hagiwara et al. (2020) indicated that the environmental factors are those that can be manipulated to enhance self-determination. Thus, family members, educators, other professionals, adult support providers, and community and societal expectations and policies can all employ strategies to improve the self-determination of people on the autism spectrum. By interventions and environmental supports being offered to individuals with lower levels of self-determination, skills can be enhanced to support opportunities such as education, employment, and independent living, which in turn will result in opportunities that naturally enhance self-determination (Hagiwara et al., 2020; Moran et al., 2021; Shogren et al., 2015). Importantly, in a meta-analysis of research into self-determination for autistic individuals, Moran et al. (2021) found that research that examined environmental influences on self-determination for autistic individuals were the least common research articles published to date. From this, it can be interpreted that practices to support self-determination for this population are also not common.

3.5.4. Family Support for Self-determination in Autistic Individuals

Two key environments for supporting self-determination in young autistic adults as they transition from school to post-school options include the young person's family and the school environment (Hagiwara et al., 2020). Research has shown, however, that families face many challenges when supporting self-determination in young people with IDD, including those on the autism spectrum (Cheak-Zamora et al., 2020; Taylor et al., 2019). Findings from the Cheak-Zamora et al. (2020) study highlighted that while caregivers report that young adults have high levels of opportunity to practise self-determination skills at home, they display low levels of capacity for self-determination in this environment. It is important to note that young people with IDD did not participate in this study; thus, the results indicated only parental or caregiver perceptions.

Taylor et al. (2019), however, conducted a qualitative study with families of young adults with IDD, including the young adults themselves. Results from this study also supported the finding that families provide high levels of support for self-determination, but that the balance among self-determination, safety, and wellbeing may be especially difficult to achieve as young adults with IDD move from the structure and safety of home and school environments. Interestingly, the family of a young adult on the autism spectrum in this study (Taylor et al., 2019) found a need to balance supporting the young person's autonomy, or the choices that he made, while pushing him to move beyond the comfort of known environments to encourage his further self-determination. These findings again supported a cyclical view of developing and demonstrating self-determination for adults on the autism spectrum, indicating that environments that can both support and enhance self-determination will most likely result in self-determination for the individual (Hagiwara et al., 2020; Moran et al., 2021; Taylor et al., 2019). Despite this, promoting self-determination from a family perspective has not received significant attention. Future research and practice are needed that focus on training, information, and ongoing support for families to explore ways to promote self-determination as young people transition from adolescence into adulthood (Hagiwara et al., 2020).

3.5.5. School Support for Self-determination in Autistic Individuals

School supports for self-determination in autistic individuals are considered equally important for both school and post-school outcomes (Kim, 2019), although studies equally indicate that the school environment is typically not supportive of self-determination for students on the autism spectrum. Qian et al. (2020) found that students on the autism spectrum showed the lowest levels of self-determination among the 12 disability groups compared across the National Longitudinal Transition Study 2012. While Tomaszewski et al. (2020) found that autistic students and their parents rated their opportunities to develop or practise self-determination in the school environment as low, educators viewed themselves as giving more self-determination opportunities in the context of the school than students or parents. These findings indicated a significant mismatch between the views of educators and the needs of autistic students with regard to how school environments are supporting self-determination (Tomaszewski et al., 2020). Likewise, Sanchez et al. (2020)

reported that, although educators highly value the promotion of self-determination, there is a disconnect between the importance that they attach to it and their level of knowledge or confidence in supporting it. Furthermore, it was observed that educators tended to simplify the concept of self-determination, identifying it with choice and autonomy, rather than considering all three basic needs of autonomy, competence, and relatedness (Sanchez et al., 2020). Although this study related to students with ID, it can be assumed that teachers are similarly, or even more, unsure of supporting self-determination in autistic students.

Furthermore, Shogren et al. (2017) found that promoting self-determination may further enhance the effect of other school-based factors such as inclusive opportunities, promoting access to the general education curriculum, enhancing students' social skills, and promoting family. These findings were significant given that these indirect opportunities accounted for over 50% of the effects influencing self-determination in school environments, suggesting that, "while targeted efforts to promote self-determination are important, creating opportunities throughout the environments where students live, learn, work, and play is crucial to enhancing self-determination" (Shogren et al., 2017, p. 174). Although the impact of naturally occurring opportunities for developing self-determination is considered important, for students with substantially reduced levels of self-determination, such as those on the autism spectrum, targeted opportunities to learn the skills associated with self-determination may also be a critical starting place.

Wehmeyer and Shogren (2017) stated that during adolescence self-determination continues to develop as individuals continue to learn the skills and actions that enable them to navigate the self-determination opportunities encountered in the environment. Similarly, Ryan and Deci (2017) and Hagiwara et al. (2020) suggested that the ongoing disparities in self-determination in adulthood for people with IDD are likely to be shaped by limited support and opportunities for the expression of self-determination throughout adolescence and into adulthood. Thus, a critical focus to support self-determination in young autistic adults becomes the teaching of and support for self-determination skills in secondary schools. One evidence-based format for learning and supporting these skills is the provision of transition-focused education that concentrates on the development of self-determination (Kohler et al., 2016).

3.6. Taxonomy for Transition Programming Framework (TTP)

Figure 3.5

Conceptual Framework with Taxonomy for Transition Programming

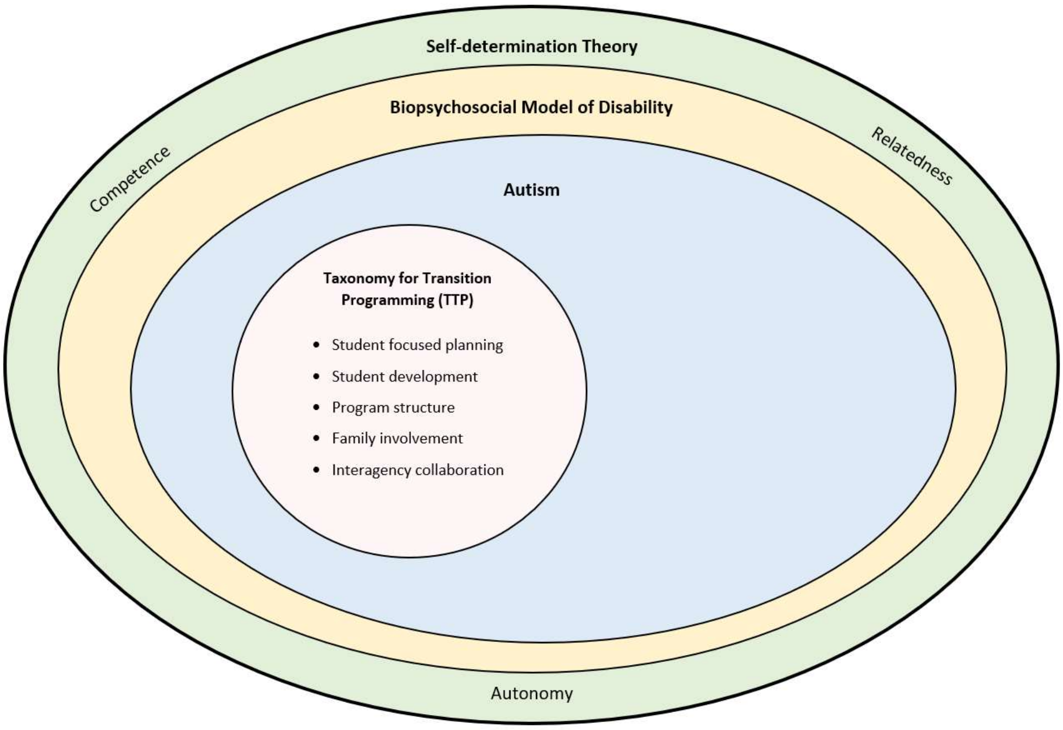


Figure 3.5 indicates how the Taxonomy for Transition Programming (TTP) was viewed as sitting within the framework of autism, as considered through the biopsychosocial model of disability and SDT. The TTP is a framework that "presents a comprehensive, conceptual organisation of transition practices through which transition-focused education and services can be developed and delivered" (Kohler & Field, 2003, p. 176), and can be used by schools to develop effective transition practices for students with disability which address both individual and environmental characteristics (Kohler et al., 2016). This framework was based on research that reinforced transition to adult roles as a complex process for all youth, and that acknowledged a myriad of factors that work together to influence the young person's life after school. It was also based on an understanding that successful transition requires the development of the young person's capabilities, alongside the provision of appropriate education and other experiences to ensure that the best outcomes are achieved (Kohler et al., 2016).

Importantly, although the TTP framework was not developed specifically for use with students on the autism spectrum (Kohler, 1996), it is a framework that encompasses each of the features that have been discussed in relation to self-determination for young people on the autism spectrum thus far. Use of the TTP framework supports a focus on self-determination. Moreover, it has been shown that the TTP framework teaches and enhances the use of self-determination for students with disabilities (Test, Fowler, et al., 2009), and for students on the autism spectrum (Mazzotti et al., 2014). Considering the biopsychosocial model of disability, the framework considers both personal and environmental influences on transition experiences and encourages the consideration of both to develop a wholistic program of transition supports. Notably, the TTP framework provides communities, schools, educators, families, and students with a common framework to work together using evidence-based practices to support optimal school to post-school transition outcomes (Kohler & Field, 2003). Finally, the TTP framework encourages the development of specific personal skills such as communication, social, and adaptive skills, choice-making, and planning skills, all of which are highlighted as being important to the development of self-determination for young people on the autism spectrum (Moran et al., 2021; White et al., 2018).

3.7. Self-determination Theory for Critical Comparisons of Transition-focused Education

Considering the TTP framework under the umbrella of SDT, and for the specific support of autistic students, is a comprehensive way to consider the effectiveness of practices being employed during this transition period. A distinguishing feature of SDT is the expectation that the three basic needs – autonomy, competence, and relatedness must be supported in effective educational environments that encourage an individual’s self-determination and wellbeing. Using SDT, it is possible to evaluate teaching practices, curricula, leadership styles, school culture and educational policies based on the extent to which they support or thwart learners’ and teachers’ basic psychological needs (Ryan & Deci, 2020). Thus, considering transition practices, specifically the TTP framework, within SDT provides a basis for critical comparisons between transition-based practices and their effectiveness for individual students. Niemiec and Ryan (2009) argued that despite

SDT's reliance on empirical methods, it is an appropriate theory to consider constructivist approaches in education. Furthermore, it is considered relevant and useful for assessing the effectiveness of education for students who experience disadvantage, such as students on the autism spectrum. SDT and basic psychological needs are important, not just because they are drivers of performance outcomes, but also because educational environments that support need satisfaction can impact on an individual's self-determination and wellbeing across the lifespan (Ryan & Deci, 2020).

This is particularly relevant for transition-focused planning, as the perspective taken when using the TTP framework is that transition planning is not an add-on activity for students with disabilities once they reach a certain age; rather it is the fundamental basis that guides the development of all educational programs in the Australian secondary schooling sector. Transition-focused education is directed towards adult outcomes, and consists of academic, career, and extra-curricular instruction and activities, delivered through a variety of instructional and transition approaches and services (Kohler & Fields, 2003). This is a very different approach from traditional models of transition-focused education whereby the student simply progresses through school until graduation with the assumption that all the skills required for successful transition to post-school options are learned through the common, core curriculum of secondary school.

3.7.1. Student-focused Planning

Student-focused planning is the first domain in the TTP framework. This domain includes the development of student-centred goals, students' participation in planning and decision making and students' evaluation of their progress in meeting their goals. Through student-focused planning, students are supported in learning about and developing skills related to self-determination (Kohler et al., 2016). The focus on self-determination in this domain is crucial, as research conducted by Wehmeyer et al. (2013) and Shogren et al. (2015) showed that individuals who exhibit higher levels of self-determination in secondary school experience both a higher QoL and higher employment rates in adulthood.

Shogren et al. (2013) found that one of the key environmental values that predicted self-determination in students with intellectual and developmental disabilities (IDD) was goal setting experience. That is, students who were more engaged in setting transition goals, and in actively monitoring and adapting these goals, were assessed as having higher levels of self-determination during secondary school. An important aspect of these findings was that the benefit was not from simply having a goal, but from the repeated opportunities to learn and practise the skills associated with setting and monitoring goals, thus supporting the finding that a positive relationship exists among those receiving instruction on self-directed transition planning, feeling empowered during transition planning, and higher levels of overall self-determination (Shogren et al., 2013). This correlated with the findings shared by Wehmeyer et al. (2013) indicating that self-determination can be learned and developed in people who experience disability.

Despite this, studies continue to show that students on the autism spectrum have minimal active involvement in the transition planning process (Chandroo et al., 2018). Although students routinely attended a transition planning meeting, the level of active involvement was very low (Chandroo et al., 2018, 2020). Additionally, Chandroo et al. (2020) found that autistic adolescents lacked knowledge about the transition planning process, with many not even aware that transition planning was in place or that activities could be accessed to support this. This was despite many students expressing an interest in being involved in their transition planning for their post-school options. Importantly, these studies were conducted in Australian schools, where there is currently neither mandate nor expectation that students with disability, including students on the autism spectrum will actively participate in transition planning (see Section 2.4).

This is extremely concerning given the tendency for students on the autism spectrum to experience high levels of anxiety associated with change and/or transition (Hatfield et al., 2017), particularly related to the transition to post-school options (Cheak-Zamora et al., 2015). Furthermore, given that difficulties with executive functioning and abstract thinking are distinct characteristics related to autism, and therefore a focus on the big picture of transition from school to post-school could potentially be problematic for many autistic students, effective preparation should be considered particularly important for adolescents on the autism spectrum (Hatfield et al., 2017). This situation highlights the issues with current limited transition planning processes, which can best be described as generic and as not specifically tailored to students on the autism spectrum (Chandroo et al., 2018; Hatfield et al., 2017).

Research has consistently shown that students on the autism spectrum need comprehensive information, careful preparation, and appropriate support to participate meaningfully in transition planning (Chandroo et al., 2018; Chou, Wehmeyer, Palmer, et al., 2017), and to experience higher levels of preparedness for their post-school transition (Kirby et al., 2020). Additionally, having and achieving clear goals increases competence (Hatfield et al., 2017). Having a supportive team is important for increasing feelings of relatedness (Hatfield et al., 2017; Ryan & Deci, 2000), and student-focused planning that is based on student goals, visions, and interests increases autonomy (Hatfield et al., 2017; Kohler & Field, 2003). Most importantly, as Koole et al. (2018) stated, "All interventions should ultimately be aimed at helping people to help themselves. Interventions that try to solve people's problems for them, no matter how well intentioned, are likely to backfire by fostering external dependencies and constraining people's agency" (p. 23).

3.7.2. Student Development

The student development domain of the TTP framework emphasises life, occupational, social, emotional, and academic skills to enhance opportunities for both school, and post-school (Kohler et al., 2016). Most research conducted with students with disability and students on the autism spectrum has found correlations to be high between these everyday living skills and school and post-school QoL, including employment, independent living, and social participation (Matthews et al., 2017; Mazzotti et al., 2014; Tomaszewski et al., 2020; Wong et al., 2021). More recent research has highlighted the fact that all required skills are not learned through a common curriculum, and that when this is combined with the understanding of the specific skills in the social, communication, emotional, executive functioning, and behavioural domains needed by autistic individuals (Cribb et al., 2019), the importance of learning these skills throughout schooling cannot be disputed. It is widely acknowledged that schools typically focus on academic performance rather than on building life skills to support the transition to post-school options (Hatfield et al., 2017; Lee & Carter, 2012).

Importantly, Taylor et al. (2019) found that people with IDD, including people with autism, have the capacity to become more self-determined through interventions that target component skills, and Carter et al. (2014) found that an ability to complete chores through daily living skills was a significant predictor of postsecondary employment for youth with disabilities, including those with autism. Wong et al. (2021) extended on this finding, indicating that the daily functioning skills exhibited by individual students determine the services that are most beneficial in transition planning. That is, students with high levels of daily functioning skills benefit from an academic focus, while students with lower levels of daily functioning skills benefit from a focus on developing the skills needed for successful transition to post-school options such as employment.

While parents and professionals in the study conducted by Hatfield (2017) advocated the individualisation of transition planning and high academic expectations, they also placed importance on adolescents developing skills for life, employment, and social situations. Although there is an acknowledgement within the biopsychosocial model of disability that communities, employers, friends, and colleagues need to make adjustments and accommodations to support each individual (Hatfield et al., 2017), few would argue that developing skills for everyday life would not benefit self-determination and overall QoL for the individual.

A key aspect of student development is the assessment of student needs before skill development is targeted (Kohler et al., 2016). From this perspective, the assessment of individual need will drive the transition planning practices implemented, and continued assessment will ensure that students are achieving the skills that they require for successful transition (Kohler & Field, 2003). As found by Cumming et al. (2020) specific assessment practices were seldom mentioned by educators or parents, indicating that individualised assessment is not occurring during transition planning. In turn, this indicates that targeted, individualised transition planning is less likely to occur.

3.7.3. Family Involvement

According to Kohler et al. (2016) there are three aspects of family involvement in transition planning. The first involves parent and family participation in assessment and planning decision making. The second, family empowerment, includes practices that facilitate meaningful family involvement by identifying family needs and providing action and support to empower families to be actively involved or to lead the transition planning process. The final aspect, family preparation, involves providing families with information and natural support to strengthen their capacity and confidence in working with others throughout the transition process, during both school and post-school options (Kohler et al., 2016). Kohler and Field (2003) highlighted the importance of all three aspects of family involvement as both the student-focused planning and the student development domains are supported and extended when families are actively involved in the transition planning process. Thus, autonomy, competence, and relatedness are enhanced for the student through family involvement in school-based practices, and this research argued that this is more likely to continue in post-school options when parents are familiar and confident in their abilities to support these basic needs.

A considerable amount of research has been conducted regarding the importance of family involvement in the transition planning process, with most outcomes showing that family involvement typically occurs at this first level; involvement (Beamish et al., 2012). As with student-focused planning, this usually includes attendance at meetings, signing transition plans, and occasional communication, rather than active support for family engagement in the transition planning process. Beamish et al. (2012) found that schools and educators did not consider family empowerment or family preparation to be part of their role, despite the finding by Cumming et al. (2020) that both parents and educators acknowledged the importance of working collaboratively.

Kirby et al. (2020) highlighted that post-school outcomes often reflect family values, beliefs, and knowledge, and therefore emphasised the importance of understanding parental expectations about their child and of improving the alignment between parent perspectives and the goals set by educators. Wong et al. (2021) reported that, regardless of the transition pathway identified, parent participation played an important role in predicting employment outcomes (Wong et al., 2021). Ryan and Deci (2017) stressed the importance of both teachers' and parents' autonomy support for the development of self-determination and positive wellbeing. Similarly, the study conducted by Tomaszewski et al. (2020) highlighted the importance of incorporating multiple perspectives when developing goals to support self-determination. Thus, the importance of active family involvement in post-school transition planning has been shown across multiple studies, particularly when the focus is on developing and enhancing self-determination in students on the autism spectrum.

Additionally, it is important to recognise that families of young people on the autism spectrum experience considerable stress when preparing for, and during, the transition to post-school options. During this time, families have considerable concerns regarding their child's level of self-determination, and often fear that their child will not develop the life skills needed to gain employment, move away from home, support themselves financially, take care of themselves and develop positive relationships (Kirby et al., 2020). Simultaneously, these are the very same goals and aspirations that most parents have for their autistic adolescent moving into adulthood (Kirby et al., 2020). Yet parents of students on the autism spectrum describe how they feel unsupported with transition planning (Kirby et al., 2020). Furthermore, they feel that the development of a transition plan (Hatfield et al., 2017), and of autonomy (Cribb et al., 2019) was ultimately their responsibility.

3.7.4. Program Structure

Kohler and Field (2003) identified that "The structures and attributes of a school provide the framework for implementing transition-focused education" (p. 179). Program characteristics, program evaluation, strategic planning, policies and procedures, resource development and allocation, and school climate, the environmental impacts of education are all important aspects of program structures and considered critical to supporting positive outcomes for students with disability (Kohler et al., 2016). It is through a relevant and appropriate program structure, including a clearly articulated mission and values, qualified staff members, and sufficient allocation of resources, that the opportunities needed for young people to develop their self-determination in schooling contexts are provided.

As discussed above, Australia is at a disadvantage with achieving effective program structures, as there are currently no specific policies to guide the implementation of transition-focused education for students with disabilities (Cumming et al., 2020). This lack of policy guidelines has an overall negative effect on the implementation of effective transition-focused education in all Australian state and territory education systems. Moreover, literature that comes from countries that do have specific policies in place, such as the United States, showed that schools and school staff struggled to implement effective transition-focused practices, and that young people on the autism spectrum still experienced inferior outcomes in comparison to those of other disability groups (Hatfield et al., 2017).

When considering these outcomes, SDT and the biopsychosocial model of disability become critical. To reiterate, the pervasive understanding of disability through the medical model has resulted in research and practices that have focused on remediating the impairments within the individual (Leadbitter et al., 2021; Williams, 2018). From this perspective, far less attention has been paid to the ways in which educational environments can be structured to support self-determination and positive wellbeing for students with disability. Thus, program structure and its components have been shown to be an area of the TTP framework that has little research support and fewer well-known practices in place (Rowe et al., 2015; Test, Fowler, et al., 2009), particularly in the Australian context (Cumming et al., 2020; O'Neill et al., 2016).

Studies that have been conducted suggested that the following factors can improve self-determination for students with disability. Inclusive education, or being educated with non-disabled peers, has been shown to predict self-determination (O'Neill et al., 2016; Shogren et al., 2013); although it may be expected to be the case, this has not yet been shown to be relevant specifically to students on the autism spectrum. Teacher knowledge and practices related to self-determination have also been shown to be important for both school and post-school outcomes (Ryan & Deci, 2017). However, Chandroo (2018) and Sanchez et al. (2020) found that while teachers value self-determination skills for students, they are unsure as to how to teach or support these skills. When this is coupled with findings by Cribb et al. (2019) that teachers have a lack of understanding of autism, it is likely that few teachers in inclusive education settings are confident in supporting students on the autism spectrum to develop self-determination. Person-centred or individualised planning has also been indicated as critical for effective transition-focused education. However, as discussed previously, this is not currently supported in Australian or Queensland schools through policies or procedures (Cumming et al., 2020; O'Neill et al., 2016). Furthermore, the lack of policy, procedure, or strategic planning has also had a negative impact on resource development and allocation. Across the board, school administrators, teachers, and parents indicate that Australian and Queensland schools are not provided with the resources to implement transition-focused practices effectively (Beamish et al., 2012; O'Neill et al., 2016).

A final key environmental factor that has been shown to impact on self-determination and positive wellbeing for all students, including those with disabilities, is school climate. School climate was suggested by Shochet et al. (2021) to influence the "degree to which students feel valued, accepted and included in their school community" (p. 20). Furthermore, it has been shown that a school climate that promotes high levels of connectedness improves student wellbeing and overall academic success, including for students on the autism spectrum (Carrington et al., 2021; Shochet et al., 2021). This relates strongly to research conducted by Nalipay (2020), who found relatedness as having the largest association with school achievement and wellbeing across cultures. Thus, it can be suggested that students who feel a sense of connectedness or relatedness within their school community are most likely to experience success across all domains of school. Considering that school climate is one of the modifiable environmental factors within program structures, it can be seen how individual student outcomes can be influenced through modifying school environments.

3.7.5. Interagency Collaboration

As with program structures, interagency collaboration focuses on setting up the environmental supports needed to ensure that young people on the autism spectrum are provided with appropriate opportunities to develop self-determination and positive wellbeing as they transition from school to post-school options. Interagency collaboration refers to collaboration among schools, families, community businesses, organisations, and agencies in all aspects of transition-focused education (Kohler & Field, 2003). It is suggested that when done well, interagency collaboration facilitates the achievement of transition goals. However, when done poorly, a lack of interagency collaboration can limit or impede transition goals (Kohler & Field, 2003). The literature suggests that in general interagency collaboration is not yet done effectively (Flowers et al., 2018), and that, in the Australian and Queensland contexts, a lack of policy support results in even poorer levels of interagency collaboration (Beamish et al., 2012; O'Neill et al., 2016).

Roux (2015) stated that, for families of autistic youth, the end of school and the transition to post-school may be especially daunting and is often described as like “falling off a cliff” (para. 1). This experience is brought about by the serious lack of support and services available during this transition period (Kirby et al., 2020), and by a paucity of adult services as the young person moves from school-based support to adult services (Cribb et al., 2019; Snell-Rood et al., 2020). Moreover, Cribb et al. (2019) found that many parents of young autistic adults described how they had been “very let down” (p. 1775) by adult services, with Chen et al. (2019) suggesting that this was because few adult services have the specialised knowledge to meet the needs of people on the autism spectrum.

Despite these findings Cumming et al. (2020) reported that the majority of parents in their study conducted in New South Wales, felt that they were part of collaborative processes in meeting the transition needs of their adolescents, while teachers spoke positively about the collaborative processes that they used to support students. On the other hand, Beamish et al. (2012) found low levels of endorsement and implementation for interagency collaboration in Queensland secondary schools. As the similarities and differences between New South Wales and Queensland secondary school transition practices are not known, it is difficult to explain this difference in findings.

3.7.6. The Importance of Transition-focused Education

Despite the too familiar focus on academic achievement in schools, it is critical to remember that schools are much more than just places of academic learning. Rather, in Western cultures such as Australia, they are the key contexts in which childhood and adolescent learning and development across all domains take place (Arnett, 2014; Ryan & Deci, 2017). Ryan and Deci (2017) emphasised that it is in the context of schools that children and adolescents learn about and develop lifelong values, self-esteem, emotional awareness, and social relationships. It is where many of the skills, knowledge, and understanding necessary for self-determination are developed, hence influencing the capacity of individuals to achieve their potential as adults. Ryan and Deci (2017) state that "Schools shape the development of the whole child, affecting intellectual outcomes as well as motivation, self-concept, and the vitality and integrity of self-development" (p. 354). Conversely, because schools play this key role in learning and development, it is imperative that they do no harm. That is, schools should "not discourage, demotivate, or kill the confidence of the students they serve or leave them feeling alienated, reactive, excluded from society, or more antisocial" (Ryan & Deci, 2017, p. 354).

From the above considerations across the five domains of the TTP framework, under the umbrella of SDT, the value of this framework for the secondary education of students on the autism spectrum is clear. Through the TTP framework, both personal and environmental needs can be assessed, and effective practices implemented to address these needs. Thus, it is suggested that positive self-determination and wellbeing can be achieved for autistic students, and that this in turn will result in improved QoL in adulthood.

3.8. Quality of Life

Figure 3.6

Conceptual Framework with Quality of Life

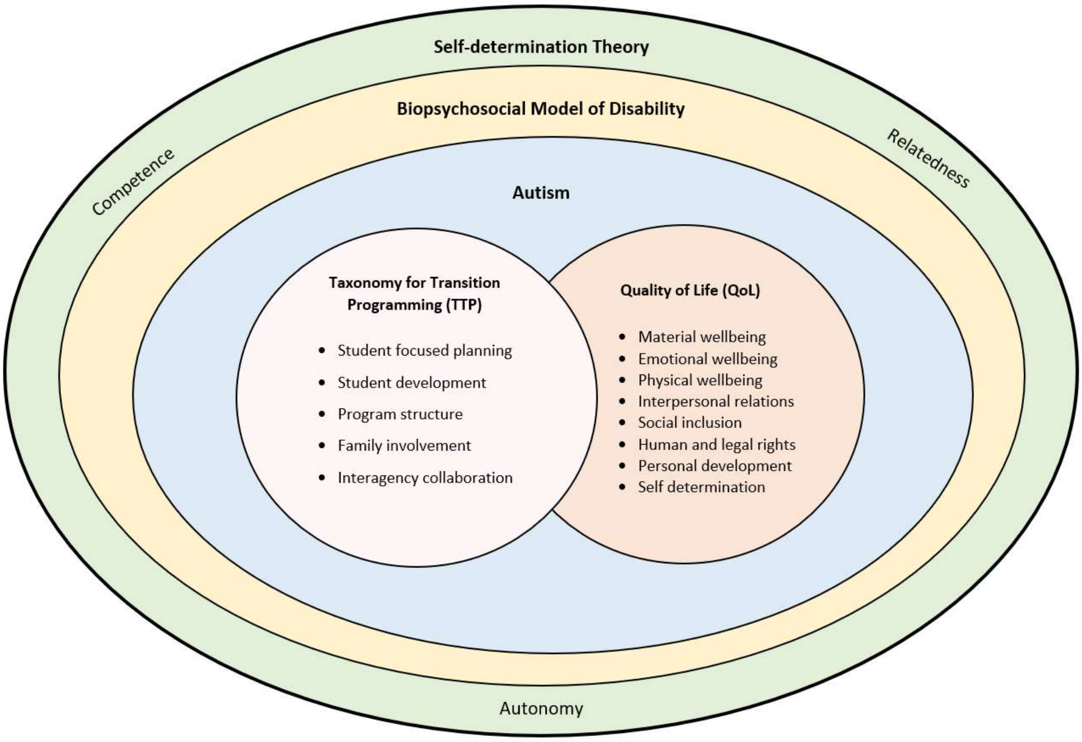


Figure 3.6 introduces Quality of Life (QoL) domains to the conceptual framework, signifying the researcher's proposition that the transition practices implemented in secondary schools have an impact on post-school QoL, self-determination, and wellbeing for autistic individuals. Schalock and Verdugo (2002) recommend that there are eight QoL domains to be considered when assessing the QoL of individuals with IDD, including those on the autism spectrum. The eight domains include material wellbeing, physical wellbeing, emotional wellbeing, interpersonal relations, social inclusion, human and legal rights, personal development, and self-determination. Each domain is then listed under three overarching factors of wellbeing, social participation, and independence. Table 3.1 lists each of the domains within the overarching QoL areas and includes a brief description of variables within each domain (Schalock & Verdugo, 2002).

Table 3.1

Quality of Life (QoL) Framework

QoL areas	QoL domains	Variables
Wellbeing	Material wellbeing Physical wellbeing Emotional wellbeing	Housing, employment, financial status Health, activities of daily living, leisure Contentment, self-concept
Social Participation	Interpersonal relations Social inclusion Rights	Interactions, relationships, supports Community integration and participation, community roles, social supports Human and legal rights
Independence	Personal development Self-determination	Education, personal skill, competence, performance Autonomy and personal control, goals and personal values, choice

The positive correction between SDT and QoL has been well established through research, including for individuals on the autism spectrum. Several studies conducted by Shogren and colleagues (2016; 2017; 2015) highlighted that self-determination is associated with increased QoL, including post-school outcomes. Chao (2017) found that self-determination has both an immediate and a long-lasting impact on QoL for autistic college students. White et al. (2018) similarly found that self-determination was a significant positive predictor of QoL ratings in a sample of young adults on the autism spectrum without ID. Finally, Kim's (2019) study provided evidence of:

> "participants' engagement in self-determined behavior and its importance in the positive experiences of their adult lives. The findings suggest that self-

> determination underlay the participants' ability to enhance their social participation and learning, actively pursue valued employment, develop positive self-identities, seek appropriate health-care services, create a stable social environment, and engage in personal development. Such self-determined behaviors as goal setting, decision making, problem solving, and self-management had positive influences on their employment status, social participation, advocacy, positive identity, and stress management" (p. 10).

Thus, a significant positive relationship between self-determination and QoL has been established for individuals on the autism spectrum both with and without co-occurring ID. It is argued in this research that this is because SDT and QoL share the core concepts of autonomy, competence, and relatedness.

Self-determination in QoL shares the same values as autonomy in SDT: autonomy, personal goals, values, control, and choice. Social participation in QoL highlights the same needs as suggested in relatedness – positive relationships with others, and a feeling of acceptance and being valued, while competence is a prerequisite for achieving satisfaction across all QoL domains – wellbeing, social participation, and independence. Moreover, meeting the needs of autonomy, competence, and relatedness across all domains correlates with the experience of emotional and physical wellbeing, as suggested in SDT (Ryan & Deci, 2017). Thus, self-determination not only is an important outcome in and of itself but has the capacity to impact the attainment of other valued outcomes in adulthood (Hagiwara et al., 2020).

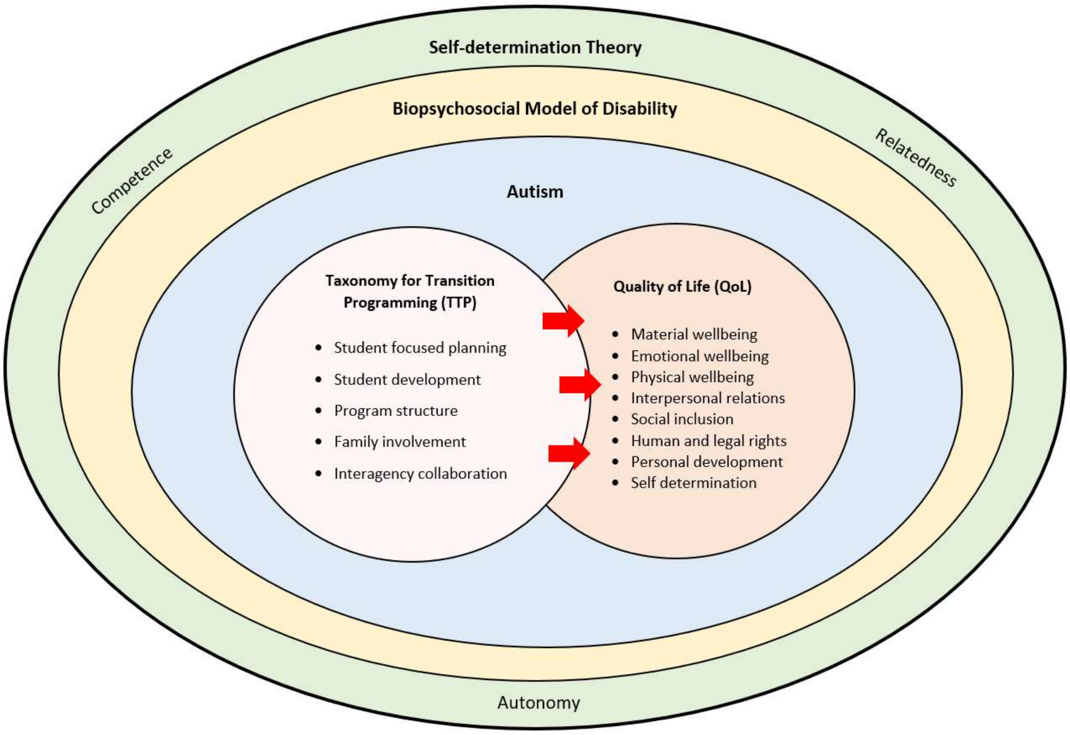
As would be expected, young adults on the autism spectrum place significant importance on self-determination in their subjective experience of QoL (Webster & Garvis, 2020; White et al., 2018). The most difficult aspect of self-determination and QoL, from the young autistic adult's perspective, is connecting their personal capacity for self-determination during this transition period with the expectations of the environment (Mattys et al., 2018). This is where the understanding of SDT and its basic psychological needs of autonomy, competence, and relatedness helps to anticipate and build self-determination. Rather than assuming that any form of assistance or support automatically detracts from self-determination, a recognition that individuals develop and express self-determination in the context of their relationships and social environments is crucial (Ryan & Deci, 2017). In this way, autistic adolescents and adults can experience self-determination and a positive subjective QoL when they view support provided as reasonable and collaborative. In fact, Curryer et al. (2018) found that adults with ID did not view support or mutual decision making as a reduction in their level of autonomy. Rather, they saw it as autonomy supportive when it involved exchanging ideas, providing information, and collaborative decision making. Mattys et al. (2018) and Taylor et al. (2019) found similar responses when researching young people on the autism spectrum and their families. Thus, interdependence with others, particularly families, has been shown across much research to support rather than to inhibit self-determination and QoL for young people, including those on the autism spectrum (Mattys et al., 2018; Taylor et al., 2019; White et al., 2018).

The most important finding across contemporary research is the relevance of self-determination skills to young adults on the autism spectrum to improve their QoL as they transition to adulthood (White et al., 2018). Furthermore, given the significance of self-determination for promoting QoL across different life domains (Schalock, 2020), it seems appropriate that both these concepts should form part of a shared understanding of the experience of autism (Sanchez et al., 2020).

3.9. Bringing It All Together

Figure 3.7

Conceptual Framework Showing Interaction Between Taxonomy for Transition Programming and Quality of Life



After consideration of the experience of autism within SDT and the biopsychosocial model of disability, the interaction between the TTP framework and QoL as young adult's transition from school to post-school options is clear. Figure 3.7 shows how this interaction was represented in the conceptual framework through the introduction of red arrows between transition practices implemented and the QoL experienced by the young autistic adult. The personal and environmental transition characteristics experienced by students on the autism spectrum will influence their subjective QoL as a young autistic adult. Therefore, this research investigated young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school QoL. These interactions were represented by the red arrows within the conceptual framework and provided crucial knowledge for stakeholders as they strive to support positive QoL for young autistic adults.

3.10. Chapter Summary

This chapter presented the conceptual framework linking the overarching theory to the various understandings about autistic individuals, their QoL outcomes, and how secondary school transition practices have influenced these outcomes. Self-determination theory underpinned the understanding brought to this research. The basic premise of self-determination theory, that all humans can achieve wellbeing when their basic psychological needs of autonomy, competence, and relatedness are met, is linked to understanding about people on the autism spectrum. The conceptual framework acknowledges that these same basic psychological needs are required for the wellbeing of autistic individuals, and that these needs are recognised when viewing autism through a biopsychosocial model of disability. Furthermore, the connection between the biopsychosocial model of disability and its focus on both individuals and their environments was linked to self-determination theory and to its recognition that the basic psychological needs of the individual are met through the environment and the communities in which they live.

Finally, the chapter considered how the TTP fits within these understandings of the autistic experience within an overarching self-determination theory. The TTP framework also recognises the three basic psychological needs of self-determination and suggests specific practices for transition programming to support students on the autism spectrum to achieve self-determination as they transition from school to post-school options. Importantly, the chapter described how these transition practices impact on the QoL of young autistic adults, and how using this framework to assess subjective QoL outcomes allowed the researcher to make connections between the TTP practices for and the QoL outcomes of young autistic adults.

CHAPTER 4: THE RESEARCH DESIGN

4.1. Chapter Overview

This chapter provides the rationale and description of the methodological approach used for this research study. It begins with a discussion of the ontological and epistemological assumptions that underpinned the methodological decisions. These assumptions led to a qualitative research orientation and the interpretivist framework of social constructivism (Creswell & Creswell, 2018). It was through the framework of social constructivism that the purpose of the research – to share the views of young autistic adults on the interaction between school-based transition practices and post-school QoL, can be achieved. Social constructivism acknowledges that together the researcher and the young autistic adults created a shared understanding of transition practices and the impacts that these have had on the young adult's post-school QoL and recognises the likelihood of multiple realities within this understanding. Similarly, the use of multiple case studies allowed for each of the individual realities to be highlighted while at the same time collectively identifying the commonalities and differences across the cases (Merriam & Tisdell, 2016).

The ethical and political dimensions of the research are explored, with specific reference to the importance of sharing autistic voice and the role that this has had in promoting a more ethical and just understanding of the research topic. Similarly, the selection and recruitment of participants, and the data collection and the data analysis strategies, are considered with regard to how the flexibility of these processes supports a proactive, strengths-based approach to the research. The methodological choices made throughout the research process significantly impacted on the outcomes and data to be shared; therefore, a clear understanding of all processes is necessary to address the credibility, transferability, dependability, and confirmability of the research (Korstjens & Moser, 2018). Throughout this chapter, the study's methodological and ethical decisions and processes are outlined and justified.

4.2. The Research Paradigm

Research paradigms relate to the ontological and epistemological beliefs that underpin the decisions made regarding the research. A paradigm was described by Guba (1990, p.17, cited in Creswell & Creswell, 2018) as a “basic set of beliefs that guide action”. Therefore, a research paradigm can be described as a basic set of beliefs that guide the actions of the researcher from the first ideas of what the research will be about, and the development of the research questions, through to crucial decisions about the methodology and recruitment of participants. According to Denzin and Lincoln (2013) a research paradigm is characterised by its ontology, epistemology, and methodology, with each in turn interacting and influencing the others. Thus, it is through my personal set of beliefs about research and the research paradigm and my beliefs regarding ontology and epistemology that I have made decisions about the methodology used in this research study.

Ontology, or ontological assumptions, refer specifically to a person’s understanding about “the nature of reality and the nature of things” (Cohen et al., 2017, p. 3). Differing ontological assumptions include the objectivist and the subjectivist conceptions of reality. Objectivist conceptions of reality view nature as objective, whereby the phenomenon exists outside the individual and imposes its will on the responsive individual. Subjectivist conceptions of reality view nature as subjective, whereby the phenomenon is constructed by individuals as they experience it (Cohen et al., 2017). Thus, a research paradigm based on a subjectivist ontological belief requires the interpretation of the subjective meanings that individuals give to their experience of the phenomenon.

Epistemological assumptions are derived from ontology and relate to the very basis of knowledge, “its nature and forms, how it can be acquired and how it can be communicated to other human beings” (Cohen et al., 2017, p. 3). Within research, epistemological assumptions determine whether the researcher believes that factual information or truth about a phenomenon exists, can be found and shared or whether there is no absolute truth and therefore what can be found and shared is the individual’s construction of knowledge about the phenomenon (Saldana, 2011).

Thus, the researcher’s ontological and epistemological viewpoint will determine what knowledge is to be sought about the phenomenon, why it is important and how it will be collected and shared. A subjective ontological and epistemological assumption implies that the nature of reality cannot be known; rather, it must be constructed between the researcher and the individual to represent the subjective experience of that individual (Creswell & Creswell, 2018). For the purposes of this research, a subjective understanding of the nature of reality, and thus a social constructivist understanding of the phenomenon, were the underlying assumptions. That is, although all young autistic adults will experience the phenomenon of transition from school to post-school options, the subjective experience of the transition process is constructed by young autistic adults based on their beliefs, thoughts, actions, experiences, and interactions as they move through the transition process. To gather and share their knowledge, individuals will describe their subjective experience of transition. In this study, the construction of understanding about the process was developed between the researcher and the young autistic adult.

4.2.1. The Social Constructivist Paradigm

Starting a research project begins with the examination of the researcher's understanding of the nature of being and of knowing or identifying the ontological and epistemological assumptions underpinning the research. From this point, decisions about research orientation and methodology are guided by these assumptions. Working under a subjectivist assumption for this research project, I acknowledge that the world exists, but that every individual interprets this world in different ways (Merriam & Tisdell, 2016). As a research paradigm, social constructivism is based on the belief that individuals seek to make meaning in their lives as they engage with the social environments in which they live. Thus, individuals "actively and agentically seek out, select and construct their own views" and this process is "rooted in the socio-cultural contexts and interactions" (Cohen et al., 2017, p. 24) in which they live.

How we pursue research depends on what the research is about, and this recognises that social constructions can vary among different social groups (Pring, 2014). The experience of transition is one that involves more than just the individual. The environment, including the people, the organisations, and the interaction between the two, also exerts an influence on the transition process (Creswell &

Creswell, 2018; Merriam & Tisdell, 2016). For young autistic adults, the transition process involves many stakeholders, including the individuals themselves, their parents, the school, their teachers, support organisations, employers, and many more. The ontological assumption that I articulated would suggest that the subjective experience of each of these stakeholders also exerts an influence on the transition process, and in turn, the individual's perceived experience with each of these stakeholders combines to construct the experience of transition to post-school options for that individual. Thus, the expectation of this study was that each young autistic adult will experience the transition to post-school options differently depending on multiple factors. Implicit in the understanding of post-school transition within a subjective ontological assumption, is the underlying theory of self-determination that posits that it is the subjective experience of individuals within their environment around autonomy, competence, and relatedness that determines wellbeing or a positive QoL.

4.2.2. The Social Constructivist Paradigm and Axiology

The premise of a social constructivist research paradigm is that we interpret our experiences in the social world to construct unique meanings. The assumption is that we gain knowledge by understanding the ways that people experience and understand the problem being investigated (Merriam & Tisdell, 2016). Research conducted with autistic individuals must therefore help us to understand the unique ways that autistic people experience and understand the phenomenon. The biopsychosocial model of disability (see Section 3.4) supports the use of a social constructivist research paradigm with autistic individuals as it emphasises the understanding of the socially and historically created understandings of the autistic person and the recognition that individuals and their environments interact to create their experiences.

Traditional research in the area of autism and the autistic experience has focused on a "negative and deficit focused picture of autistic personhood" (Milton & Bracher, 2013, p. 27). It has been suggested that this is in part due to the failure of researchers to engage fully with the lived experience of autistic individuals who have often been deprived of the opportunity to express their own perspectives, particularly related to their own positive wellbeing and resilience. This can pose significant ontological and epistemological problems, resulting in the exclusion of autistic worldviews from the production of knowledge and in a consequent misunderstanding of autistic people and the environments needed to encourage their wellbeing (Bolte & Richman, 2019; Fletcher-Watson et al., 2019; Milton & Bracher, 2013; Pellicano et al., 2019).

Following from the ontological and epistemological assumptions, the axiological assumptions define what is valued or valuable within the creation of knowledge. Axiological assumptions by the researcher therefore underpin the value placed on who is involved in the construction of knowledge, and which knowledges will be emphasised and shared. As the parent of a young autistic adult (see Section 1.5), I find the proliferation of this negative and deficit-focused world view of the autistic individual prejudicial to everyone involved: the autistic person themselves, their families, and the various organisations with which they are involved.

The aim of acknowledging this world view is therefore not to deny that values are involved in the research, but rather to acknowledge and explain the values that are present. The personal values and opinions underpinning this research reflected a strengths-based focus of the experiences of autistic individuals, their families, and the wider community in which they live. A strengths-based approach focuses on the strengths or the positive attributes of the person, rather than on the negative attributes (Niemiec et al., 2017). It positions individuals as resourceful and resilient and able to influence their own outcomes positively despite the adverse conditions that they may face (Muniandy et al., 2021). Furthermore, a strengths-based approach identifies any personal or environmental constraints that might be holding back an individual’s positive development. These values, in turn, align closely with the beliefs of self-determination theory (Deci & Ryan, 2002), whereby all individuals have the potential to achieve high levels of wellbeing when provided with positive environments that support autonomy, competence, and relatedness within their lives.

4.2.3. A Qualitative Research Orientation

Researchers often consider research methodologies as set, natural, and unquestionable (Strunk & Locke, 2019). However, this is not the case. Although two primary research orientations, quantitative and qualitative, are often spoken about and both are considered to have very different purposes, Pring (2014) explained that this binary view of research, quantitative or qualitative, is unhelpful and that the true reality lies in the many possibilities across this spectrum. The research orientation that is most suited to the specific research study remains the decision of the researcher and will be influenced by that researcher's ontological, epistemological, and axiological assumptions, and the goals of the research.

Given the ontological, epistemological, and axiological foundations described for this study, a qualitative research orientation was considered the most appropriate to meet the research goals. Merriam and Tisdale (2016) state that "Qualitative research defies a single, simple definition" (p. 9), and that underneath the banner of qualitative research there are many different research methodologies that align themselves to qualitative research. Rather, qualitative research needs to be considered with regard to its key characteristics – understanding and meaning; the researcher as the primary instrument of data collection and analysis; and the process as primarily inductive and richly descriptive (Creswell & Creswell, 2018; Merriam & Tisdell, 2016).

The first characteristic of understanding and meaning relates to the qualitative researcher's interest in "understanding how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences" (Merriam & Tisdell, 2016, p. 39). To the qualitative researcher, words and pictures, rather than numbers, are the key forms of data. Within the qualitative research orientation, the focus is on understanding the participant's perspectives, not that of the researcher. Thus, in the second characteristic of qualitative research, the researcher is considered the primary instrument of data collection and analysis (Merriam & Tisdell, 2016) with the constructive orientation acknowledging that researchers themselves will also influence this data collection and analysis. Thus, the researcher obtains information through a reciprocal gathering and sharing of information between the researcher and the participant as they observe, question, clarify, summarise, and interpret (Cohen et al., 2017). As such, there are seen to be both positive and negative aspects of the qualitative research orientation. The positive experience derives from the researcher being able to be responsive and adaptive to the data gathering process. For the purposes of this study, this positive aspect was a critical consideration as it allowed responsive methodologies to be aligned to the requirements of the autistic participants. The negative experience of qualitative research is grounded in the acknowledgement that "all humans have shortcomings and biases that can influence the research" (Merriam & Tisdell, 2016, p. 11). However, rather than trying to eliminate these biases, Pring (2014) suggested that they should be identified, monitored, and reported.

The third characteristic of qualitative research is the inductive data collection process. Researchers gather data to build concepts, hypotheses, or theories rather than deductively testing hypotheses. In qualitative studies, researchers build towards theories from knowledge gained from the participants in the form of themes, categories, and concepts (Merriam & Tisdell, 2016). Creswell and Poth (2018) suggested that, while the most common analysis in qualitative research is inductive, the use of both inductive and deductive approaches can be applicable. The inductive approach is used to analyse the meaning of information shared, while a deductive approach can be used to structure these meanings within an identified framework. In the current study, both inductive and deductive methods were used. The perceptions of participants were analysed deductively by categorising the information shared by participants according to the established Taxonomy for Transition programming (TTP) framework (Kohler, 1996) and the Quality of Life (QoL) framework (Schalock & Verdugo, 2002). Once distributed across domains, the data were then analysed inductively, developing themes from the information shared across domains.

As part of this process, the fourth characteristic, rich description, comes into play. Qualitative research is descriptive in nature. Words and pictures are used to convey what has been learned by the researcher. These descriptions form detailed descriptions of the context, the participants, their experiences, and their understanding (Merriam & Tisdell, 2016). Creswell (2017) categorised this rich description as verisimilitude, or the process of making things real. That is, the reader of qualitative research should experience the feeling of being present with the research participants and with their interpretations of the phenomenon.

To achieve the characteristics of qualitative research and gather data, researchers should go into the real-world contexts of the participants and immerse themselves in their views and life experiences. The design of the research needs to be flexible and emergent, responding to the changing conditions of the study as it progresses. Thus, qualitative researchers work towards keeping methods dynamic to respond most effectively to the contexts of the research (Bailey, 2019). To meet the dynamic and situated needs of this research study, and to gain insights into the interaction between Queensland secondary school practices and post-school QoL, the qualitative research methodology chosen was a case study approach.

4.3. Methodology

Methodology refers to the development of the approach to designing and implementing the research study. The focus of methodological design is to answer what, where, when, who and how of the research (Johnson & Christensen, 2017): What information will be collected; from whom it will be collected, where and when this will take place, and most importantly, how this will be done. The why of the research study has already been revealed through the discussion regarding the ontology, epistemology, and axiology of the researcher. From this point, the researcher makes the decision about which data will be collected and analysed, from whom those data will be collected, and where, when, and how. In qualitative research, there are many methodological approaches that can be used (Creswell, 2017; Creswell & Poth, 2018; Merriam & Tisdell, 2016).

4.3.1. Case Study

Case study research is a qualitative approach in which the researcher explores a bounded system (a case) or multiple bounded systems (cases) through detailed, in-depth data collection (Creswell & Poth, 2018). A key aspect of case study research is in the identification of the bounded system that is the ***case*** and the use of this case to understand the phenomenon under investigation (Merriam & Tisdell, 2016). Because of the construction of understanding between the researcher and the participant in case study research, it is considered most appropriate for use in research situated within a constructivist paradigm (Cohen et al., 2017; Yin & Campbell, 2018). A case study research approach focuses on the process, interactions, and relationships with the topic and, as such, it is most effective for answering ***how*** and ***why*** questions in research (Yin & Campbell, 2018).

The current study was suited to a case study approach as it sought to answer the overarching question, ***How do young autistic adults perceive the interaction between secondary school transition practices and post-school quality of life***, with the three identified sub-questions all relating to ***how*** and ***what***. Thus, by using a case study research methodology I came to know the case intimately within its real-world context (Stake, 2005) and I used each case to examine the how and what of the school to post-school transition process. Through the collection and analysis of the participant's responses, this case study research shared the views of young autistic adults about their experiences of the transition process.

The bounded system of this case study research was the school to post-school transition for an individual autistic student who attended a mainstream Queensland secondary school. The case was investigated through data collected from both young autistic adults and their parent or carer and focused entirely on the perceptions of the participants of the transition process and its impact on their QoL. Throughout the write up of each case, rich descriptions were provided to allow the portrayal of the experiences of the individual participants (Merriam, 1998; Stake, 2005). Thus, the bounded system of the case was the focus of the description and the analysis within the research.

Case study research has both advantages and disadvantages. A key advantage of the case study is its rejection of a single reality relating to the phenomenon. Rather, it is assumed that there are multiple realities, understood by various participants within a situation. Importantly, the researcher's interpretation of the cases is only one of the many possible realities (Merriam, 1998). Additionally, case studies are more easily understood by a wide audience because of their descriptive, story like style, and they often capture the unique features of the case that larger scale quantitative data may not (Cohen et al., 2017). It is, however, these very advantages that can result in the disadvantages of case study research. Primarily, because of the smaller number of participants, and the unique interpretations of the phenomenon shared by these participants, case study research is not considered replicable, representative, or generalisable. Thus, it is difficult to make inferences or to draw cause and effect conclusions from case studies owing to the uniqueness of each case (Creswell & Poth, 2018).

4.3.2. Multiple Case Study

Multiple case study is the study of more than one case in relation to the phenomenon being considered (Merriam, 1998; Stake, 2005). Miles et al. (2014) suggested that “we can strengthen the precision, the validity, and the stability of the findings” (p. 33) by using a multiple case study design, as it is likely to offer a range of both similar and different findings that can be used to inform the interpretation of the data. Furthermore, “the more cases included in a study, and the greater variation across cases, the more compelling the interpretation is likely to be” (Miles et al., 2014, p. 33). In this research, the recognition that each young adult experienced the transition process and QoL differently was important to the underlying assumptions of the study. It was not expected that each case would share similar information, but it was hoped that across the cases there would be both commonalities and differences that would contribute to the knowledge of how transition practices from school to post-school impact on QoL for young autistic adults. Thus, the key advantage of multiple case study for this research was the strengthening and validation of findings across cases.

An important aspect of multiple case study is the cross-case analysis. Cross-case analysis involves looking across the rich data provided by each case and considering both commonalities and differences related to the phenomenon or bounded system of the research (Stake, 2005). The key disadvantage of a multiple case study is that the requirement for cross-case analysis can sometimes lead to a reduction in the focus on each case for its inherent importance (Creswell & Creswell, 2018; Stake, 2005). That is, the cross-case analysis becomes the focus of multiple case study research to the detriment of the individual cases. With this consideration in mind, it was important that I respected each case for the individual story that it provided. Each case, in and of itself, shared valuable information about the interaction between secondary school transition practices and post-school QoL. Each case deserved its story to be shared in detail and with fidelity, ensuring that the focus was on the individual case, with the cross-case analysis enhancing these findings, not detracting from them. As Stake (2005) suggested “the section reporting the cross-case analysis should be shorter than the sum of the case studies, yet it should convey the most important findings” (p. 41).

4.3.3. The Role of the Researcher

The role of the researcher within the social constructivist paradigm is one of meaning making (Pring, 2014). The researcher seeks to understand individuals' interpretations of their world with regard to the phenomenon being investigated. Implicit in social constructivism is the belief that the world does not determine the experience of individuals, but that individuals interact with and shape both the world and their experience of it. In this way the social constructivist experience is complex and complicated, and the researchers' role is to navigate these complexities as they seek to understand the research participants' interpretations and understandings of the world around them (Pring, 2014). Because there is no single, observable reality, but instead multiple interpretations of a phenomenon, researchers do not find knowledge; they construct it (Merriam & Tisdell, 2016). As a social constructivist researcher in this research project, my role was to seek to understand the individual participants' interpretations of the experience of transitioning from school to post-school options and the impact that this experience had on their QoL as young adults, and together to construct an understanding of the lived experience of their transition.

A key role for the social constructivist researcher is the explicit sharing of the processes used to construct the individual's interpretation of the phenomenon. For this to occur, in-depth and detailed descriptions of the research process must be provided (Johnson & Christensen, 2017). All stages of the research process are influenced by the paradigmatic assumptions of the researcher, and, as such, must be clearly identified and described. From the formation of the research questions through to the final analysis of the shared interpretations, the step-by-step decisions and process are provided as a rich description of the researcher's experience. This, in turn, must be evaluated with regard to its influence on the participants and on the experiences that they share (Creswell & Creswell, 2018; Milton & Bracher, 2013). The simple act of speaking with the researcher about their QoL and transition experiences will, in turn, influence the research participants' understandings of this phenomenon.

Roles are negotiated socially and historically (Creswell & Creswell, 2018). That is, they are formed through the interactions that have occurred throughout the transition process. As young adults move from the context of school to the various post-school contexts available, they negotiate a variety of roles – adolescent, student, employee, son/daughter, friend, and young adult. Within each of these roles lies the potential to construct an understanding of the transition process. Thus, the young adults' interpretations of these roles and of the perceived impact on their autonomy, competence, and relatedness are key to the formation of their ideas, feelings, and beliefs about this transition. As the researcher, my role was to elicit these ideas, feelings, and beliefs about each topic, while maintaining the integrity of the research participants' interpretations of their experience (Cohen et al., 2017). Maintaining the integrity of the research participants' construction of the transition experience became even more critical as a nonautistic researcher representing the interpretations of autistic individuals (see Section 1.5).

4.4. The Ethical and Political Dimensions of the Research Design

4.4.1. Ethical Dimensions

Conducting research with human participants requires consideration of the ethical and political dimensions of the research study. Ethical considerations refer to the care, attention and respect provided to the research participants throughout the research study, while the political dimensions refer to the attitudes and decisions made by the researcher, and importantly, to the reasons why these decisions were made (Creswell & Creswell, 2018). For both the ethical and the political dimensions of the research design, it is critical to acknowledge that these aspects relate to every feature of the research conducted, not just to the methodology of the study (Hammersley & Traianou, 2014). From the first ideas that the researcher puts forward, to the development of the research questions, decisions about the underlying theory and conceptual framework, the data collection and analysis process, and the final writing and publishing of the work were all underpinned by ethical and political decisions made by the researcher. As is discussed throughout this section, some of these decisions were structured and formalised, while others were implicit, situated decisions made on a day-to-day basis throughout the research study (Danaher et al., 2013; Reid et al., 2018).

Ethical standards in research are the principles of right and wrong conduct (Merriam & Tisdell, 2016). They involve questions of value and judgement, theoretical perspectives, and methodology. Most importantly, they protect the rights and welfare of research participants and provide accountability for researchers. The National Statement on Ethical Conduct in Human Research (2018) are ethical guidelines that have been developed for the express purpose of guiding ethical research in Australia, and that are implemented through various ethics governing committees such as the University of Southern Queensland Human Research Ethics Committee. These guidelines stipulate the formal, universal ethical requirements for conducting research with human participants (Danaher et al., 2013; National Health and Medical Research Council, 2018).

Ethics approval for this research study was obtained from the University of Southern Queensland's (USQ) Human Research Ethics Committee in May 2019 (see Appendix A). Ethical approval standards are primarily concerned with two main themes regarding human research: risk and benefit; and participant consent (National Health and Medical Research Council, 2018). Receiving ethical approval indicated that the USQ Human Research Ethics Committee was satisfied that I had sufficiently considered the risks and benefits for the participants in the research study, and that informed consent was able to be obtained from participants before they engaged in the research.

4.4.2. Situated Ethics

It must be acknowledged, however, that while ethical approval had been received, this was not the end of the ethical process for this study. There is much deliberation within the research community as to whether these formal, universal standards can meet the needs of specific participants and specific contexts where research is carried out (Reid et al., 2018). Instead, receiving ethical clearance is suggested as being only the starting point, with continual ethical decision making required in response to specific contextually related situations that will arise throughout the research project (Usher & Simons, 2000). Danaher et al. (2013) suggested that "generalised ethical code and principles do not always generate positive outcomes for members of marginalised communities engaged in research projects" (p. 145), and, as such, research projects with marginalised communities, such as the autistic community, will require its own process of constant ethical decision making. The authors explained that the formal, universal code of ethics is to be used first and foremost, with ethical issues and challenges being continually monitored and responded to throughout the entirety of the research project. It is suggested that the two are used most effectively when they work together to provide an all-encompassing view of ethical considerations within research (Danaher et al., 2013). Thus, the use of universal, formal ethical principles such as those in the National Statement on Ethical Conduct in Human Research (2018) and the associated approval process was considered the first stage of research design and approval. Following this, the use of situated ethics throughout the entire research project allowed me to consider the multiple and often conflicting interests and perspectives of the participants and contexts, even though ethical approval was received for the consent forms developed for the project, and participants signed these forms at the beginning of the interview giving consent to their participation in the study. As the researcher, I needed to make continuous decisions to gauge if the interview were causing the participant significant distress, and therefore, if the interview could continue.

4.4.3. Risk and Benefit

Risk is defined by the National Statement on Ethical Conduct in Human Research (2018) as the "Likelihood that a harm (or discomfort or inconvenience) will occur" (p. 12) and considers the possible severity of the harm and the consequences that may result from this harm. Benefit is not as easily defined; however, it is generally considered to be the gaining of an advantage or access to something positive. In the context of research, therefore, benefit refers to gaining an advantage or something positive as a result of participating in the research. Thus, consideration of risk and benefit must balance the potential for harm against the potential for benefit. While risk is primarily determined with regard to the individual, benefit can be considered from the perspective of the individual, a specific group, or the wider community (National Health and Medical Research Council, 2018). Therefore, the potential risk of participating in the research for young autistic adults and their parents, needed to be balanced with the potential benefit for the individuals, the autistic community, and the wider community in which these individuals lived.

Within the current research study there were two distinct participant groups: young autistic adults; and their parents or carers. For the parents and carers, the risk of harm was considered low and addressed through benefit. That is, a minimal risk of harm based on possible discomfort in talking about difficult situations, and about their child's transition to post-school options, and inconvenience in terms of time were addressed. Importantly, adults over the age of 18 are thought to be sufficiently capable of managing these low levels of discomfort and inconvenience and therefore the potential benefits of the research are balanced against the potential risks (National Health and Medical Research Council, 2018). Young autistic adults, however, are deemed to be at increased risk of experiencing harm through participation in research. People on the autism spectrum are deemed to fit under the category of "People with cognitive impairment, an intellectual disability, or a mental illness" (National Health and Medical Research Council, 2018, p. 73). This categorisation implies that additional levels of risk to benefit analysis must be conducted and approved by the full USQ Human Research Ethics Committee.

Cohen et al. (2017) suggested that while ethical decisions are based on ethical principles, these decisions can become very complex when different ethical principles conflict with one another. Conducting research with people on the autism spectrum is one such example where abiding solely by the ethical principle of "do no harm" may in fact serve to reinforce the marginalisation experienced by this population and perpetuate systemic discrimination against this research population (Parson, 2019). This study sat clearly within these two conflicting ethical principles. The first is the ethical consideration of ***do no harm,*** including psychological harm such as anguish, significant emotional upset, anxiety, or stress (National Health and Medical Research Council, 2018). Considering that people on the autism spectrum typically experience elevated levels of anxiety and/or stress as a co-occurring condition (Clark et al., 2015; van Heijst & Geurts, 2015), it may be considered ethically incompatible to conduct research with autistic participants. However, the ethical and political guidelines presented in the United Nations Convention on the Rights of Persons with Disabilities (United Nations Convention on the Rights of Persons with Disabilities, 2006) established that all people with disabilities, regardless of their specific disability, have the right to express their views on all areas that affect their lives, and to have these views heard. Therefore, it is essential that research is conducted with participants on the autism spectrum.

The use of situated ethics provided a method for addressing both ethical principles with this research study. That is, the universal code of ethics was applied with regard to the initial research project design and the accountability of the researcher, while situated ethical considerations were applied throughout the research project with regard to the specific participants, specific contexts, and the ethical challenges that were presented throughout the study. This ensured that the ethical imperative of ***do no harm*** was applied to both the psychological harm that may have been caused by engaging in the research and experiencing some level of anxiety and stress, and the psychological harm that may have been caused by not engaging in the research and not being accorded a level of respect and integrity that recognises the autistic individual as an autonomous, social agent.

The need to balance risk and benefit, ensuring that young autistic adults could participate in the current research study and share their world view, without being at risk through experiencing high levels of anxiety, was addressed through the principles of universal design. Universal design, when applied to research, means that the researcher will, from the outset, design research participation strategies that are flexible, adaptable, and multifaceted (Harrington et al., 2013; Loyd, 2012). Thus, the strategies typically used to address participant risk were applied to a scale of adjustments that could be chosen by individual participants and their families as needed. An example of an adjustment included the researcher meeting the parent or carer of the young adult first to discuss the levels of anxiety experienced by the young person, potential topics that might trigger anxiety, and the signs that might indicate that the young person was experiencing heightened levels of anxiety. Harrington et al. (2013) and Tesfaye et al. (2019) suggested that a close working relationship with the young autistic adults' families allowed the researcher access to significant knowledge about the young people, how they experienced anxiety and how they managed their anxiety. This knowledge, in turn, provided the researcher with confidence to undertake the research interview without putting the participant at increased risk of experiencing harm owing to high levels of anxiety. On the other hand, the universal design strategy was not used by all participants or their families, as many were confident that they could take part in the research interview without experiencing anxiety (see Eric, Section 5.10). A list of risk mitigation strategies, and the scale from which the participant could choose, is provided in Table 4.1. All strategies were supported by the researcher's personal experience of working with young autistic people, and by previous research conducted with young people on the autism spectrum (Harrington et al., 2013; Loyd, 2012; Tesfaye et al., 2019).

Table 4.1

Risk Mitigation Strategies

Strategy	Scale
Researcher and parent meeting prior to the interview	Meet several times prior to the interview – Meet for the first time at the interview
Participant meeting with the researcher prior to the interview	Meet several times prior to the interview – Meet for the first time at the interview
Co-construction of information sheet detailing time, place, and number of interviews	1 x 1 hour interview – As many interviews as needed
Co-construction of information sheet detailing support services	Additional support services added – No additional support services added
Advocate	Advocate present for interview – No advocate

4.4.4. Informed Consent

Informed consent is considered the cornerstone of research ethics (Cohen et al., 2017), as it implies that individual participants are making the decision to participate in the research with a full understanding of what this participation will entail, including the risks and benefits that it may present for them. The importance of consent is never questioned and is covered in the National Statement on Ethical Conduct in Human Research (2018) under “the requirements of consent” (p. 16). Within this understanding of consent there are two conditions listed: consent should be a voluntary choice; and consent should be based on sufficient information about and adequate understanding of both the proposed research and the implications of participation in it. These conditions imply that the participant has the competence to make this decision, and that individuals will make correct decisions if they are given the relevant information (Cohen et al., 2017). It is therefore incumbent on the researcher to ensure that participants in the research are competent to make such decisions.

An increased level of complexity is added to the ethics of consent when participants are considered to have limited capacity, or limited ability, to understand the purpose of the research and its implications, and to consent voluntarily to participate. The National Statement on Ethical Conduct in Human Research (2018) stated that participants with a cognitive impairment, an intellectual disability, or a mental illness are "entitled to participate in research", but that "their distinctive vulnerabilities as research participants should be taken into account" (p. 73). As individuals on the autism spectrum are included within this group of participants, ethical consent requires the consideration of competence and what this means for young autistic adults.

As with risk and benefit, the use of universal design principles supports the researcher's ability to meet all legal requirements confidently, while at the same time ensuring that autistic participants are given the opportunity to participate in research if they choose to do so. The basics of universal design for consent provide support for the communication differences that are often experienced by autistic individuals. In the National Statement on Ethical Conduct in Human Research (2018), the requirement of consent implies that participants will exercise the right of voluntary choice with regard to participating in a research project, and that this choice will be based on sufficient information, and an adequate understanding of the research and of the implications of participation. The deficit-based model of disability reinforces underlying assumptions that autistic individuals would not understand the information provided, nor what would be expected of them during the research or the possible implications of this. As a result, a person with autism would not be capable of providing informed consent to participate in research (Loyd, 2012). By contrast, a strengths-based approach that sits within the biopsychosocial model of disability recognises the potential difficulties associated with the effective communication of information, while at the same time, acknowledging that the provision of the information in a format that is relevant, easily accessible, and well supported ensures that the individual is able to provide informed consent (Loyd, 2012).

Strategies specific to the provision of informed consent provided a range of options to address the diverse capacity of autistic individuals. These options ranged from written consent forms for young adults over the age of 18 who were able to provide consent, to verbal assent to be re-negotiated with the participant after consent was obtained from the young adult's legal guardian or carer (Loyd, 2012; National Health and Medical Research Council, 2018). All documents related to informed consent, including consent forms (see Appendices G, H, I, and J), assent forms, and participant information sheets were made available in a range of formats including audio recordings, written documents and documents using visual or pictorial information (see Appendices C, D, E, and F). Consent, or assent, depending on the context were provided through written, verbal, or nonverbal agreement (National Health and Medical Research Council, 2018).

A key strategy employed in the current research project was the co-construction of the participant information sheet involving the researcher, the participant, and the participant's advocate (see Appendices E and F). The participant information sheet is the means by which the researcher provides information about the research project, and about the ways in which the participant will be involved, including the benefits and risks of participation (National Health and Medical Research Council, 2018). Given the underlying basis of working with individual participants to adopt strategies to support their participation, the provision of a single information sheet was not appropriate. Instead, an outline of the research project that allowed the inclusion of strategies specific to the individual was deemed as more appropriate, and as more likely to meet the principles of universal design. Thus, prior to collecting data, the researcher and the advocate would spend time with the autistic individual, learn about the individual's preferences, and design an information sheet based on this information to be provided to the participant. Specifically, information relating to the number, time, and place of interviews, the preferred communication styles, and the support services that could be accessed if the participant experienced distress throughout the research process was included on the information sheet during the process of obtaining consent.

4.4.5. Confidentiality and Anonymity

According to the National Statement on Ethical Conduct in Human Research (2018), confidentiality is the requirement that participants will not be identified or easily identifiable from the research. Confidentiality is considered important because it provides a level of security and confidence for participants that they will not be negatively affected by the information that they share. From the researcher's perspective, ensuring confidentiality can mean that participants may share their knowledge, experiences, and ideas more freely (Cohen et al., 2017).

For this study a semi-structured interview format was employed whereby participants spoke about their perceptions of their own QoL and their own transition to post-school experiences. Within these discussions, there was no information gathered that the participant did not want to share. This was ensured by following the lead of the participants throughout the interviews. Instead, at times participants asked how "blunt" they could be in their topics of conversation (see Eric, Section 5.10). Despite this, several strategies were used to protect the confidentiality and anonymity of the participants (Cohen et al., 2017; Merriam & Tisdell, 2016). The participants were given the opportunity to choose a pseudonym to represent themselves in the research data. The specific locations where the participants lived, attended school, and engaged in post-school activities were generalised. Town names were not used, and schools were referred to in terms of their descriptions rather than their names – for example, large metropolitan state school. Details shared by the participants about any other persons were referred to in general terms such as "my friend", or that person was also given a pseudonym.

Although confidentiality and anonymity were protected by the strategies described above, it is recognised that these strategies in and of themselves do not guarantee confidentiality (Surmiak, 2018). A level of detail for each participant was maintained to protect the valuable contextual data required for the research. Each participant's age, gender, living circumstances, employment, and relationship status were maintained throughout the study (see Appendix Q). This level of detail, even with a pseudonym, could potentially result in participants being identified by those who knew them (Surmiak, 2018). Howe and Moses (1999) suggested that qualitative research requires a level of detail that complete confidentiality cannot provide. The removal of all contextual information would render the data gathered as general information that could not be analysed across contexts. The thick descriptions required for case study research additionally requires contextual information to build the picture of the case. Thus, additional consideration for maintaining confidentiality was needed. This included ensuring that participants were from multiple communities across southeast Queensland, so they were not known to one another or from within a single community; ensuring that participants were aware of their right to withdraw consent from the research study if they did not want to share this level of detail publicly; providing participants with an opportunity to edit transcripts before data analysis was conducted; and ensuring that a strengths-based focus was used throughout the research to highlight the positive aspects of their achievements and goals. Thus, although complete confidentiality could not be ensured, I was confident that all participants were comfortable with the level of confidentiality provided, and that sharing their stories through this research would not result in their being harmed.

4.4.6. Political Dimensions

Consideration of the political dimensions of the current study fell under two key areas – politics and power. The broader context of politics and power influences all aspects of the research conceptualisation and implementation, including methodological choices (Bailey, 2019; Tilley, 2019). The World Health Organisation’s (2011) World Report on Disability found that educational policy design and standards do not always account for the needs of people with disabilities, and that existing supportive policies and practices are not always enacted. Thus, the political stance taken in this research was to share the perceptions of young autistic adults about one area of educational policy and practice: transition from school to post-school options in Queensland secondary schools. Given that Queensland schools have no mandated requirements for the transition planning for any students on the autism spectrum beyond the Senior Education and Training (SET) plan (Beamish et al., 2012; O'Neill et al., 2016), the need for representations of the voices of autistic students is critical. While it is acknowledged that small qualitative studies do not provide the notion of causality that is often preferred by policy makers, there is no reason why qualitative data cannot be used as part of the evidence-base for policy decision making (Maxwell, 2020; Tilley, 2019). Additionally, the findings from this research might be useful to other young autistic adults, their parents, teachers, and schools, as they consider what might work to support more effective transition to post-school options.

To do this however, researchers find themselves in a position where each decision in the research process must be addressed through these ethical and political dimensions. This "ability to make decisions in the research process represents the significant power of the researcher" (Parson, 2019, p. 16). The power inherent in the position of researcher, as an authority within the community, must be acknowledged and addressed to ensure that the voices of the participants are able to be shared. In qualitative research, this power is most appropriately addressed through reflexivity whereby a perspective is shared, as well as how this perspective shapes what is derived from the data and from the completed analysis (Creswell, 2017).

It is important to also acknowledge that power imbalances in this study were multidimensional. Although I acknowledge the power inherent in the position of researcher, I also acknowledge the power inherent in the position of participant. The young autistic adult participants had significant power over the researcher, a nonautistic outsider. As the autistic world view was shared, I, the researcher, needed to provide a non-critical and non-judgemental approach to the experiences shared by the autistic research participants as I interpreted the information provided (Milton & Bracher, 2013; Pellicano et al., 2019). My role as the researcher was to collect the information as provided, and as intended by the research participant, while attempting not to place personal nonautistic value judgements on the information provided. It was through a strengths-based approach to autism that this was addressed (Niemiec et al., 2017). That is, all the data provided by the participants were interpreted through a strengths-based approach that assumed that the participants were informed, capable young adults who were willing to share their perceptions as they experienced them.

4.5. The Data Collection Strategy

Merriam and Tisdale (2016) discussed the fact that data are not out there waiting to be collected. Firstly, they have to be noticed by the researcher and treated as data for the purpose of the study. In this way the data that are collected are determined by the conceptual framework, the purpose of the study, the research questions, and the participant sample selected. Thus, which data are collected and the methods for collecting those data will be underpinned by the ontological, epistemological, and axiological understandings brought to the research by the researcher. The data collection strategies for this research project are now described.

4.5.1. Sampling Strategy

The sampling strategy used for qualitative research studies is typically referred to as a non-probability sampling method (Merriam & Tisdell, 2016), which indicates that research participants are actively recruited and selected rather than being randomly assigned. This sampling strategy does not require large sample sizes or the random allocation of participants, as it seeks an in-depth understanding of the perceptions of the participants, as they are seen to have the knowledge and experiences related to the phenomenon that the researcher is seeking to understand. With non-probability sampling, the specific sampling of participants who meet a specific set of requirements is called ***purposive sampling*** (Johnson & Christensen, 2017). This method is considered appropriate provided that the researcher is addressing ***what*** and ***how*** questions about the research participants' understanding of the experiences that they have had, rather than looking for possible causation or correlation outcomes.

To begin purposive sampling, it must first be determined which selection criteria are essential and that the criteria directly reflect the purpose of the research (Creswell & Poth, 2018). In this case study, a two-tiered process of purposive sampling was used (Patten, 2015). Firstly, the researcher selected the case and set the boundaries (Stake, 2005). Following this, because the methodology chosen was a multiple case study, the purposeful selection of multiple participants who met the criteria for the case was carried out. Initially, the case for this research study was defined as ***a young autistic adult who had transitioned from a Queensland secondary school to post-school options within the last five years***. This case was considered most appropriate to investigate the insights of young autistic adults into how secondary school transition practices impacted on post-school QoL as these young people would have direct experiences of the transition process and of QoL as young adults.

Importantly, a key part of identifying the boundaries or criteria of the case is to also identify which criteria will not be considered (Stake, 2005). Many studies aim to recruit participants with as many similarities or commonalities as possible (Creswell & Creswell, 2018). For example, studies of autistic individuals often recruit all male or all female participants, with an expectation that gender will play a role in the outcomes. Patten (2015), however, suggested that one criteria option is to attempt to capture as much variation as possible. It is posited that “Any common patterns that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared dimensions to a setting or phenomenon” (Patten, 2015, p. 283). This maximum variation sampling strategy was used when recruiting participants for the current study. That is, sampling sought to represent that widest possible diversity of characteristics and life experiences of autistic individuals that was possible in a small sample size. Thus, maximum variation in age, gender, schools attended, post-school options chosen, and level of support needs were selected (see Appendix Q).

Following the identification of the case, various organisations that support young autistic adults in southeast Queensland were contacted and provided with the research participation flyer (see Appendix B). Organisations that agreed to distribute the flyer included autism support groups, disability employment agencies, disability support agencies, psychological services, autism specific Facebook groups, and autism specific education services. From this initial round of recruitment, a small number of possible participants contacted the researcher, with three people fitting the criteria of the case, as previously stated: ***a young autistic adult who had transitioned from a Queensland secondary school to post-school options within the last five years***. Although many parents expressed an interest in participating in the research, their young adult did not want to take part in the research.

With additional participants required, changes were made to the recruitment strategies. The most important change regarded the case criteria. After the difficulties recruiting young adult participants were discussed with my supervisors, the decision was made to change the criteria from ***a young autistic adult who had***

transitioned from a Queensland secondary school to post-school options within the last five years to ***a young autistic adult who had transitioned from a Queensland secondary school to post-school options***. I went back and approached the same organisations, but this time I integrated two additional strategies. The first was to record a short video introducing myself and my research study. This video was uploaded to a Facebook page and linked to various autism specific Facebook pages, so that young adults could see the researcher and listen to what the research was about before deciding whether to participate or not. The second strategy was to take a more personalised approach to distributing the research flyer via the various organisations. Rather than sending the flyer to the organisation to distribute to the local community support group, I organised to attend support group meetings, where I introduced myself to the people attending the group and spoke to them about the research as well as handing them the flyer. With these additional strategies, I was able to recruit six more participants, taking the total to nine. I then stopped actively recruiting participants as I was confident that the research participants recruited would provide valuable information about their QoL and transition experiences. The strategy of reaching the point of saturation was not considered appropriate for this research strategy (Merriam & Tisdell, 2016). As each individual case was viewed as being unique and distinct, no saturation point could be reached with data collection.

Sampling strategies for qualitative research tend to use smaller sample sizes. The size of the sample is determined by a number of factors relevant to the study's purpose, including the qualitative methodology used and the type of data gathered. A key consideration is the volume of data generated during qualitative research. As qualitative case study research can use multiple forms of data collection from interviews, observations, and document analysis, Stake (2005) suggested that between four and 10 case study participants are suitable for multiple case study research. More than this number would produce unmanageable numbers of data. For the current study, nine young autistic adult participants were recruited. Additional supporting data were collected from seven parents of the young autistic adult participants, with one parent providing information about both of her daughters, and with one adult whose parent was unable to participate. Thus, a total of 16 participants was interviewed.

4.5.2. Semi-structured Interviews

In case study research, the researcher may use a variety of data collection techniques including observation, interviewing, and document analysis (Merriam, 1998; Stake, 2005; Yin, 2014). The decision as to which of these techniques will be used should be based on the kind of information that is to be collected (Merriam, 1998). For this study, the information to be gathered was how the young autistic adults interpreted the interaction between secondary school transition practices and their current QoL. It was suggested by Merriam (1998) and Stake (2005) that, when gathering details of the individual's life that the researcher cannot observe, interviews are the most appropriate form of data collection. Specifically, semi-structured interviews can be effective for accurately representing the individual participant's thoughts, feelings, and beliefs (Merriam, 1998; Stake, 2005). Thus, semi-structured interviews were the primary data collection technique used throughout the research as the multiple and past experiences that influenced the data provided about QoL and transition experiences could not be observed directly.

Additionally, semi-structured interviews provided the researcher with the ability to capture the individual's perspective of an experience within identified themes in a consistent and systematic way (Yin, 2014). The semi-structured interview format allowed the researcher to structure the interview questions to ensure that each domain in the TTP framework (student-focused planning, student development, program structure, family involvement, and interagency collaboration) and the QoL framework (material, physical and emotional wellbeing, interpersonal relations, social participation, rights, personal development, and self-determination) was adequately addressed, while also providing opportunity for the specific beliefs or concerns of the young adults and their parents to be captured. The information sought in the research was about the interaction between two already established frameworks – Kohler's TTP (1996) and Schalock's Framework for QoL (Schalock & Verdugo, 2002) for people who experience disability. Hence the research questions (see Appendices K, L, M, N, O and P) were developed and structured within the categories of these two frameworks. The aim of the research questions was to guide the participants' discussion about the phenomena within these categories, while allowing areas of particular relevance and interest to be introduced by the participants themselves (Bloomberg & Volpe, 2019; Stake, 2005). An initial study of the interview questions was conducted with two young autistic adults to ensure that the questions developed were likely to gather relevant and informative data. Both young autistic adults were well known to the researcher and were able to provide feedback on all aspects of the semi-structured interview process: the researcher's interactions such as tone and level of engagement; use of visuals to support participant responses; and the order of questions. From the initial study, several changes were made. These included primarily a reduction in the number of visual cards (Adolescent/Adult Goal Setting Tool [AAGST]) (Ashburner, Jones, et al., 2019a) used throughout the interview, and changes to the way that these visual cards were collected together in groups. These initial interviews were not recorded, and data from them have not been shared in the research project.

For this study, a semi-structured interview was conducted with each of the participants and their parent or carer. One interview was conducted with each participant, and one interview with each parent/carer, either with the young adult or separately. The interviews lasted between 30 minutes to 1 hour 30 minutes, depending on how much the individual participants wanted to share. Each interview was recorded digitally, and the researcher added to this recording with the use of written notes describing the researcher's thoughts, interpretations, and feelings throughout the interview process (Merriam, 1998). The semi-structured interviews took place over a period of six months, from November 2020 to May 2021.

Owing to the specific characteristics of the young autistic adults, the interview process was flexible in its design (Jacobson et al., 2012). Each interview was conducted in a different location, at different times, and in different formats, with each of these adjustments designed to respond to the individual needs of the participants and their parents. Prior to each participant interview, the researcher spoke to the participant and the parent to co-develop the information sheet and to ensure that the decisions regarding how the interviews were to be conducted were finalised. Some interviews were conducted with the participant and the parent separately, while other interviews were conducted together; that is, the young adult and their parent engaged in the semi-structured interview together. During the latter, the young adult and the parent responded to specific questions directed to them;

however, they also supported the comments of each other as the interview progressed.

As people on the autism spectrum may experience difficulties in communicating through the traditional methods such as written and verbal language interactions, alternative communication methods were used throughout the research study. These methods included the presentation of written information for participants either in regular text or in an easy read format (Sutherland & Isherwood, 2016), the use of the Adolescent/Adult Goal Setting Tool (AAGST) visual cards to provide visual support for the participants during the interview process (Ashburner, Jones, et al., 2019a), the option of using Photovoice to focus on participants' specific interests (Danker et al., 2019; Do et al., 2021), and/or the option of written or technology based communication methods such as response diaries or online chats (O'Brien et al., 2014). The preferred method of communication for the participant was determined during the familiarisation and relationship building stage of the research. The choice of interview format was discussed with the parent during the initial contact stage or parent interview to determine the most likely preferred interview format. This was then clarified with the young autistic adult before the first interview was conducted. All young adults chose to participate in a one off, face to face interview, with some young adults choosing to use the AAGST cards (Ashburner, Jones, et al., 2019a) during the interview.

The AAGST cards were developed to support autistic adolescents and adults to communicate effectively regarding their goals and aspirations in the areas of independent living, social participation, and community participation. The cards include wording and images depicting important aspects of adult life and were co-designed with autistic individuals to ensure the wording and images were representative of specific topics to autistic individuals (Ashburner, Jones, et al., 2019b). Using the AAGST cards was found to facilitate conversations between autistic people and those supporting them to discuss their goals and priorities in adult life (Ashburner, Jones, et al., 2019b). During the interviews conducted for this research, the AAGST cards were used by some participants to support their interviews with the researcher by providing a visual reminder and/or representation of the areas they wanted to talk about.

Additionally, the semi-structured interviews were conducted in a relaxed, informal manner. O'Grady (2016) and Tesfaye (2019) reported that participant's felt respected when an interview took on a more casual, as opposed to a formal interview style. This, in turn, reinforces the relationship between the researcher and the participant and encourages the participants to be more open and honest with their responses. For many of the semi-structured interviews, this relaxed, informal interview approach, coupled with the security of having the parent or advocate present meant that the young autistic adults were very forthcoming with the information that they shared. In all cases, the interviews went longer than initially intended, and none of the young adults requested a break or needed to end the interview early.

4.5.3. The Data Analysis Strategy

The data analysis process in this qualitative research study deployed thematic analysis through coding. Thematic analysis is a process that aims to bring order to, and to make sense of, the large numbers of data that will be collected during semi-structured interviews, and/or observations (Miles et al., 2014). For this research project, data analysis was used to interpret the data collected in the semi-structured interviews. Before thematic analysis or coding can occur, all the interview data were transcribed verbatim from the interview recordings (Miles et al., 2014; Saldana, 2016). Transcription was conducted by a transcription service. After the transcripts were received, I read through them several times, while listening to the original recordings, both to familiarise myself again with the interview data and to make any corrections to the transcripts themselves. Corrections made were minimal and included minor corrections to words or abbreviations that were misunderstood in the transcription process, and a reduction of repetition to ensure that the transcript was clear and easy to read (Kvale & Brinkmann, 2007). Care was taken to ensure that the meaning of the transcript was not altered during these adjustments. This initial familiarisation with the data is a key process undertaken before moving into the first cycle of data analysis (Saldana, 2016), and relates to phase one of thematic analysis: familiarising yourself with your data, as suggested by Braun and Clarke (2006).

Following this familiarisation process, the corrected transcripts were sent to the individual participants and their parents so that they could be read, and participants could make any adjustments to the transcripts as required. These adjustments included corrections to the transcript as well as adding or deleting data as they chose. This process is referred to as member checking (Creswell & Poth, 2018; Merriam & Tisdell, 2016) and is considered a critical cycle in qualitative data analysis where the sharing of participant perceptions is fundamental to the purpose of the research. Thus, for this study, member checking was critical to ensure that the participants were happy with the information being shared throughout the study. While it was assumed that the parents would be comfortable reading through the transcripts, it was acknowledged that not all participants may have been able to read long written transcripts to provide their feedback. Therefore, as part of the initial meeting and relationship building between the researcher and the parent, the researcher spoke to the parents about the importance of the young adult being a part of this process and the parent agreed to use a suitable method for sharing the transcript with their young adults as needed. For some young adults who were comfortable with written forms of communication, the transcript was sent directly to them as well as to their parents. For the other young adults, the transcript was sent to the parent and the parent then talked through the transcript with the young adult, receiving verbal feedback on the information. In this way, the parent could then make the necessary adjustments before returning the transcript to the researcher. For Paul, one young adult whose parent was unable to be interviewed, participant Bruce's mother, a close friend of Paul's and a key member of the autism support group agreed to go through Paul's transcript with him.

After the familiarisation process was complete with the adjusted transcripts, each transcript was uploaded into NVivo. NVivo is a software tool used to support qualitative researchers in managing large data sets (Johnson & Christensen, 2017), and can make the process of qualitative data analysis more efficient and streamlined. Using NVivo allowed each of the interview transcripts to be stored in a consistent, safe space. Furthermore, NVivo was also able to be used to conduct the first and second cycle data coding in conjunction with the physical manipulation of the data.

Miles et al. (2014) suggested that the process of coding typically occurs across multiple stages: first cycle data coding, second cycle data coding, and third cycle data coding and so forth. First cycle coding methods, or generating initial codes, are used to detect recurring patterns within the data, and to assign themes or codes to these patterned chunks of data. This can be done through a variety of coding approaches, with each approach supporting a particular focus or purpose. Furthermore, they explained that the specific coding approaches used should be related to the specific types of knowledge that the researcher wishes to highlight, and that more than one approach can be used to support the purpose of the research (Miles et al., 2014). Given the study's research questions, and the focus on participant perception of the interaction between transition practices and post-school QoL, coding approaches designed to highlight participant voice and subjective experience within established frameworks of knowledge were used in the first cycle coding of data. Approaches suggested by Miles et al. (2014) and Saldana (2016) to support this knowledge include descriptive, values, and in vivo coding. A coding strategy was developed outlining the different levels of coding strategy used and their relationship to the research question (see Appendix R).

For this research, the first cycle coding was a deductive coding process. Deductive coding conducted using a set of provisional starting codes prior to data analysis (Creswell & Creswell, 2018). These starting codes used the combination of the two frameworks considered central to the conceptual framework, the TTP framework (Kohler, 1996) and the QoL framework (Schalock & Verdugo, 2002). Codes were set up using the domains from these two frameworks in NVivo. The researcher read through each of the transcripts in detail, assigning the participants' shared knowledge to the appropriate codes. For example, data shared about emotional wellbeing was coded in the NVivo QoL emotional wellbeing code. Values coding was also included in this first cycle deductive coding process with each of the framework domain codes being assigned a value, either positive or negative. In this way, a participant comment about QoL emotional wellbeing could be coded as either positive or negative depending on whether participants were commenting on a positive aspect of their emotional wellbeing such as "I was so happy", or on a negative aspect of their emotional QoL such as "I get really anxious" (see Appendix S).

In vivo codes were also used as part of the first cycle coding process. In vivo codes are codes that "use the language and the words of the participants" (Johnson & Christensen, 2017, p. 576). These codes were considered key to this study to share the voices of young autistic adults about their current QoL and about how secondary school practices impacted on their QoL. As a result, the first cycle of data analysis included a combination of deductive coding into predetermined codes, with positive or negative values being assigned to the codes and using the ***voices*** of the participants and their parents for in vivo codes.

In the second cycle of data analysis, the information included in each of the determined codes was then analysed for categories or themes that were referred to by the individual participant (Miles et al., 2014). These coding strategies in turn allowed the researcher to examine underlying ideas, assumptions, and conceptualisations rather than focus solely on what the participant had stated (Braun & Clarke, 2006). That is, what did the participants, and their parents, share in terms of their positive and negative perceptions of their QoL across all eight QoL domains? Equally, what did the participants share in terms of their positive and negative perceptions about the transition practices they experienced during their time at school under the domains of the TTP? In this way, following the second cycle of data analysis, the researcher had established the perceptions of the young autistic adults and their parents about each of the QoL and the TTP domains. The perceptions of the young autistic adults, and their parents, about their current QoL were used to answer Research Question 1: ***How do young autistic adults perceive their current quality of life?*** To support this finding, NVivo coding charts were produced showing the level of positive versus negative perceptions shared by all participants. Using these charts was the first strategy used to determine the overall perception of the young adult, and whether it was primarily positive or negative (see Appendix T).

It is important to note here that the young autistic adults' perceptions were given greater emphasis than those of their parents. That is, the key purpose of the research was to share the perceptions of the young adults. The primary role of the parents' perceptions was to support or add value to the perceptions of the young adult. In this study there was a very high level of association between the young autistic adults and their parents across the majority of QoL domains, with only small differences in some QoL and TTP domains.

The next level of data analysis related to finding and interpreting the interactions between QoL outcomes and transition practices, as shared by the research participants. For this process to occur, each code was printed and glued to large sheets of paper organised across the QoL and TTP domains with the value of positive and negative perceptions. From there, these large sheets were laid out next to one another so that the researcher could easily see the overall perception of QoL and how this related to the overall perception of TTP (See Appendix U). For example, did high response levels about social and emotional skill development in the student development domain of TTP relate to positive emotional wellbeing in post-school QoL? This physical comparison of data is an effective and often preferred form of data collection to using only computer software representations (Merriam, 1998; Stake, 2005). Large, easily viewed representations of the data collected assisted in the analysis of data by the researcher of case specific perceptions. These sheets were also used as the second strategy to determine the overall perceptions of the young adults, and whether they were primarily positive or negative.

The third and final data analysis process involved focusing on each case specific analysis and considering these from a cross-case perspective. In multiple case studies, it is this cycle of coding, or the final level of thematic analysis that provides the foundation for cross-case analysis (Miles et al., 2014; Saldana, 2016). Following data analysis of each individual case, cross-case analysis is carried out with the goal of identifying those themes that cut across cases and that can be used to deepen understanding and explanation and to enhance transferability to other contexts (Miles et al., 2014). Thus, similar patterns in the perceptions of each young adult on the autism spectrum, will offer a deeper understanding of how secondary school transition practices interact with post-school QoL. For this research study, the cross-case perspective involved identifying key themes across the nine cases relating to both perceptions of QoL and perceptions of TTP and the interactions between the two frameworks. For example, two key themes identified were ***young autistic adults experience high levels of positive QoL outcomes as a result of high levels of family support across all QoL domains*** and ***the parents and families of young autistic adults experience limited family involvement in transition planning practices***. From the cross-case themes, possible enabling factors related to the implementation of effective transition practices in secondary schools were identified. Using the above examples, the enabling factor determined was ***schools should provide greater***

levels of family involvement, family empowerment and family preparation within transition programming.

4.6. The Credibility and Trustworthiness of the Study

Credibility and trustworthiness of the research were supported through a range of strategies. Throughout the study, there was clear articulation across the conceptual framework, research questions, data collection, and data analysis to establish the researcher's position within the research undertaken and to support the credibility of the research. The use of multiple case studies allowed a deeper understanding of the phenomenon and supported the possibility of transferability to other contexts (Stake, 2005; Yin, 2014). Trustworthiness was established through member checking of all the data collected and a peer review process within the data analysis. Lastly, a clear audit trail was provided throughout the research process to allow an open and transparent review of the research processes (Miles et al., 2014; Saldana, 2016).

4.6.1. Triangulation of Data

The purpose of the current research was to share the perceptions of young autistic adults of the interaction between secondary school transition practices and their post-school QoL. Thus, the perceptions of the young autistic adults regarding transition practices and QoL were key to this study. The triangulation of data is the process of corroborating evidence from different data sets, with different data collection methods and from different individuals (Johnson & Christensen, 2017). The primary form of triangulation for the current study involved collecting data from different individuals. Within-case triangulation of data was provided through the interviews with both the young autistic adults and their parents (Korstjens & Moser, 2018). That is, the primary role of the parent's perception was to support or add value to the perceptions of the young adult. Thus, if the young autistic adults suggested that they experienced a positive level of material wellbeing, and if their parents also suggested that they experienced a positive level of material wellbeing, this level of compatibility of data provided a higher level of credibility than if only one person were interviewed. In this study, there was a very high level of correlation between the young autistic adults and their parents across the majority of QoL domains, with only small differences in some QoL domains such as interpersonal relations and social participation. For example, the number of friends whom the young adult had, was reported consistently by both the young adult and the parent; however, the perception of how this impacted on the young adult's QoL varied between the two. While the young adults were content with the number of friends whom they had and perceived that number of friendships positively, their parents shared concerns about the young adults' limited number of friends and perceived this negatively. These findings supported previous research and identified different young adult and parent perceptions in the QoL domains of interpersonal relations, and social participation (Bishop-Fitzpatrick et al., 2016; Mattys et al., 2018). For TTP, there was generally a high correlation between the perceptions of the young adults and their parents. That is, the young adult and their parent generally agreed with the school transition practices, and about which were positive, and which were negative.

Another form of triangulation used for this study was using multiple case studies. In this way, data were sourced from multiple individuals; thus, common themes across the multiple case studies provided a high level of credibility for the data shared (Miles et al., 2014). Furthermore, Stake (2005) recommended the use of multiple case studies to illuminate consistencies both across cases and across the phenomenon being studied, and to provide research findings that are "as clear and suitably meaningful" and "free from our own biases" (Stake, 2005, p. 77) as possible.

4.6.2. Member Checking

Member checking is a process whereby the researcher asks the participants to check their findings for accuracy and to ensure that the data shared are representative of the participants' perceptions and understandings (Johnson & Christensen, 2017). Member checking can take place at various intervals during the research process, from initial checking of the interview transcripts to confirming that the themes identified are consistent with the perceptions of the participant (Johnson & Christensen, 2017). For this study, member checking occurred at the initial level of checking interview transcripts to ensure the accuracy of the data that were shared with the researcher. Although the transcripts were shared with all participants, only one young adult requested small adjustments to be made to the transcript data.

The ontological and epistemological assumptions underpinning this study were those of a constructivist understanding of what can be known and how it can be known (Cohen et al., 2017; Merriam & Tisdell, 2016). This understanding implied that the researcher, together with the participants, constructed the knowledge shared in the research findings. Thus, it was understood that the intention of this qualitative research was not to provide confirmable data, but rather that the data provided would show how the interactions between the participants and the researcher constructed an understanding of the phenomenon under investigation. From this perspective, participant confirmation of final themes was not sought.

4.6.3. Trustworthiness

The preceding sub-sections on triangulation and member checking were used to support the trustworthiness of the research study. Trustworthiness considers the dependability, credibility, transferability, and confirmability of the research findings (Korstjens & Moser, 2018). Together, each of these four considerations supports the reader to determine how accurate the research findings are, and how these findings can be used to further their understanding of the phenomenon and its applications.

Dependability and credibility refer to the consistency of the outcomes of the research study and to the extent to which the research can be acknowledged and analysed by individuals not involved in the research study (Johnson & Christensen, 2017). Both dependability and credibility were supported in this research through clear articulation among the conceptual framework, research questions, data collection, and data analysis. That is, alignment across every aspect of the research study from design through to implementation and final write up was clearly identified and described from the position that the researcher took. In this way the construction of the research findings between the researcher and the participants was acknowledged and articulated.

Transferability or generalisation has traditionally not been the intention of qualitative research (Johnson & Christensen, 2017). Instead, qualitative research is focused on providing rich descriptions of the experiences of specific individuals.

Moreover, the individual participants in qualitative research are not randomly selected but rather according to specific criteria determined to elicit the greatest amount of knowledge regarding the phenomenon (see Sampling Strategy, Section 4.5.1). For these reasons, it cannot be assumed that the findings of this qualitative research could be transferred to other individuals and contexts.

Despite this, qualitative research is being recognised as being more transferable or generalisable through the structured way that the research is recorded and the way that the readers of the research associate or generalise the research to the populations with whom they work (Johnson & Christensen, 2017). Yin (2018) and Tilley (2019) explained that generalisations are rarely taken from single qualitative research studies. Instead, they are usually based on multiple sets of research. As the researcher describes the details about the people, settings, times, and contexts of the research, the reader can make naturalistic generalisations from the research findings based on similarities between the research participants and the individual contexts considered (Stake, 2005).Thus, qualitative research, such as this study, may help the people familiar with the phenomenon to use the research findings to build an understanding that can, in turn, inform their practice.

4.7. Chapter Summary

In Chapter 4, I presented the research paradigm underpinning this study, along with the design and methodology that followed this research paradigm. The ontological, epistemological, and axiological understandings of the research guided the development and implementation of the research methodologies. Each of these was presented in detail, as required in qualitative research studies. A qualitative case study method of collecting data about participants' perceptions of the interaction between secondary school transition practices and their post-school QoL, through semi-structured interviews, and its justifications was also presented in this chapter.

Detailed data analysis strategies, to provide the reader with an understanding of the process undertaken in the analysis of the individual case study and cross-case analyses, were explored. The credibility and trustworthiness of the research design and implementation were considered, and the limitations were discussed.

CHAPTER 5: YOUNG AUTISTIC ADULTS' PERCEPTIONS OF THEIR QUALITY OF LIFE

5.1. Chapter Overview

In this chapter, I present the results of the qualitative data analysis related to Research Question 1: ***How do young autistic adults perceive their current quality of life?*** This first research question addressed how young autistic adults perceive their quality of life (QoL). This was a critical question to be addressed prior to the consideration of the second research question: ***How and why have secondary school transition practices influenced the quality of life of young autistic adults***? That is, identifying how young autistic adults perceive their current QoL first enabled a more effective analysis of how transition practices have impacted on their QoL. It has been suggested the people on the autism spectrum can have different perceptions about the world from those of their nonautistic peers (Spath & Jongsma, 2020). Therefore, it would follow that the subjective QoL of autistic people could be very different from that of their nonautistic peers. This chapter highlights the perceived QoL of each of the research participants. Both the research participants and their parents shared their perceptions of the autistic adults' QoL since completing secondary school and transitioning into post-school life. Across all participants, there was a high concurrence between the perception of the young adult and the perception of the parent. That is, both the young adults and their parents expressed similar views across the QoL domains.

The analysis was conducted within the bounds of the QoL domains as discussed by Schalock and Verdugo (2002). Schalock and Verdugo (2002) and Schalock (2004) suggested that there are eight QoL domains to be considered when assessing the QoL of individuals with disabilities, as previously detailed in Section 3.8. Furthermore, each domain is listed under three overarching factors of wellbeing, social participation, and independence. Table 5.1 lists each of the domains within the overarching QoL factors and includes a brief description of the variables within each domain (Schalock & Verdugo, 2002).

Table 5.1

Quality of Life Domain Descriptions

Quality of Life factors	**Domains**	**Variables**	**Domain descriptions**
Wellbeing	Material wellbeing	Financial status Housing Employment	Personal possessions that are important to individuals How much individuals can use money for things that they want and need
	Physical wellbeing	Health Activities of daily living Leisure	Energy levels Being able to get medical help Health and lifestyle
	Emotional wellbeing	Contentment Self-concept	Happiness and safety How individuals feel about their life
Social participation	Interpersonal relations	Interactions Relationships Supports	Type of support and help individuals receive Relationships with family and friends The types of activities that individuals undertake with the people in their life
	Social inclusion	Community integration and participation Community roles Social supports	The activities and things that individuals do and would like to do in the community The people with whom individuals do things and the places where they go in their community

Quality of Life factors	Domains	Variables	Domain descriptions
	Rights	Human Legal	Individual’s right to privacy How individuals are treated by people How much individuals are listened to
Independence	Personal development	Education Personal skill Competence Performance	The things about which individuals are interested in learning The things that they enjoy and that are important to them
	Self-determination	Autonomy and personal control Goals and personal values Choice	The choices and decisions that individuals make about the areas that matter to them in their life

The perceptions of the autistic adults and their parent/s were analysed, and are presented, within these eight QoL domains. Throughout the analysis, both deductive and inductive coding methods were used (Miles et al., 2014). Deductive coding was used first to code participant data according to the QoL domain to which it related. In this way, data were coded for each participant into the eight predetermined QoL domains as described above in Table 5.1. Inductive codes were then used as a second level of coding to determine the key factors that were highlighted within the QoL domains for each participant.

This chapter begins with a brief description of the case participants and sets the location context of the research. Each case is then considered in terms of the eight QoL domains as described above. Throughout the QoL domain accounts, a rich description of the lives of each case is interwoven to build a picture of each case and to provide thick descriptions as required in multicase design (Merriam, 1998; Stake, 2005). Throughout the analysis, significant similarities and differences were found with regard to each young adults' perception of his or her QoL. This was expected owing to the heterogeneous nature of autism and the different experiences that each individual participant had had.

5.2. Introduction to the Participants

Nine young adults and their parents were interviewed for this study (see Appendix Q). The participants themselves represented the significant diversity that is present within the autism community (Bottema-Beutel et al., 2020; Pellicano et al., 2019). While all the participants identified as being a person on the autism spectrum, they had very different life experiences, including their: gender, age, age of diagnosis, living arrangements, employment, tertiary study, and support received. This diversity was considered a benefit to the research as it helped to highlight both the commonalities and the differences in experiences for autistic individuals across the spectrum of autism experience (Patten, 2015). In the research participant group, there were five males and four females interviewed. Six participants were emerging adults (18 – 25 years) (Arnett, 2014), with three participants being in the adult age brackets (26 – 29 and 30 - 39 years), with a recognition that many adults report similar events to the emerging adulthood experienced by these age groups (Arnett & Mitra, 2020). Two participants were attending university, and six participants were employed. Of the participants interviewed, three lived independently, while the others lived with their families. Three of the participants received moderate to high levels of National Disability Insurance Scheme (NDIS) funding and support, two participants received low levels of NDIS funding and support, while the remaining four did not receive any NDIS funding or support.

Interviews were conducted with each participant and her or his parent. Seven of the parents were mothers. Two participants were sisters hence their mother was interviewed regarding the experiences of both girls. One interview was conducted with the mother and stepfather together. One parent was not able to be interviewed; however, the young adult wanted to participate regardless. Whether the interviews were conducted with the young adult and parent together or separately was the decision of the participant and the parent. The focus of the interviews was to gather the young adults' perceptions of their QoL. The use of parent interviews was to provide support for what the young adult shared. The young adults chose the pseudonym used for their case study, while the parents were not given pseudonyms, instead using their title. This decision was made to help to signify the importance of the young adults' perceptions.

5.3. John

5.3.1. Introduction

John is 23 years old and was diagnosed with autism as a young child. He currently lives in a small apartment in a regional city with his older brother, who also has a diagnosis of autism. John always attended mainstream schools while receiving assistance from Special Education Program support staff at the schools. Throughout his life, John has received high levels of support from his mother, father, stepfather, and extended family, as well as from outside organisations. Five years ago, John graduated from a large regional high school, and he currently works on a permanent part-time basis, Monday to Friday, as a kitchen hand in a local café. John is extremely active in his local community, and has a busy schedule that comprises work, daily living activities, going to the gym and playing sports, social activities with friends, and accessing the community with his support worker. Overall, John presented as having a very high QoL post-school, with both John and his mother expressing this throughout their interviews.

Interviews were conducted separately for John and his mother, with his mother being interviewed first and John several days later. John opted for his mother to be present as an advocate during his interview, and he used the Adolescent/Adult Goal Setting Tool (AAGST) (Ashburner, Jones, et al., 2019a) visual cards throughout the interview to support his conversation. John has well-developed language skills and spoke in a very precise, controlled manner, ensuring that he answered each question to the best of his ability. Throughout the interview, John showed evidence of using specific social and conversational skills such as using the interviewer's name, initiating eye contact, and using humour. After the interview was completed, John continued engaging with me (the interviewer), eagerly telling me more about his interests in cooking and drawing.

5.3.2. Quality of Life Domains

John’s mother expressed that she is confident that John has a very high QoL across most domains, and she spoke very clearly about how well things are going for him post-school. This was shared through comments such as “He’s doing very, very well. Life is amazing”, and “He’s a very happy young man, very fulfilled”. She went on to say that she is confident that John “thinks his life is pretty good”. During John’s interview, he did indeed share these positive perceptions of a high QoL, particularly in the areas of wellbeing and social participation. From John’s perspective, he has high levels of self-determination, with him expressing throughout the interview that “I can do/go wherever I want”, and that he “feels confident, comfortable” making decisions for himself and talking to his family about these decisions.

5.3.3. Wellbeing

Material Wellbeing. Material wellbeing relates to an individual’s financial status, living arrangements, and employment (Schalock & Verdugo, 2002). Across all three areas, material, physical and emotional wellbeing, John perceives his QoL very highly, and this is strongly supported by his mother. Regarding finances, John’s mother stated that “Financially, he’s sitting very securely”, and that “He has all the things he loves and wants around him”. John admitted that he works with his mother on “money managing”, and that he uses his money to do the things that he wants to do. John shares all household bills with his brother and uses the rest of his money to support his social life – for example, going out with friends, paying for gym, and sporting club membership, and buying the things that he loves such as art supplies and Lego.

The initial decision to move in with his brother was made by John, and while this was unexpected the decision was fully supported by his mother and soon afterwards John moved to the unit. John and his brother, while provided with support, live independently, and share both the household chores and the bills. John described his role as “doing all the cooking”, “cleaning the kitchen” and “cleaning the bathroom”. During the discussion about cleaning the bathroom, John stated, with a grin, that he “hasn’t done that yet”, and that “it’s a tough job, but you got to do it”.

He also stated that he gets on well with his brother “most of the time”. John did disclose that “I found it stressful when I first started moving in”, but now he is settled and enjoys living in his own place.

After leaving school, John worked at his stepfather’s café and completed a training course in hospitality before gaining employment in a local café. John expressed a great deal of pride and contentment with his work in hospitality and sees it as “a very important job”. He spoke eagerly about his work hours, the work that he does and how much he enjoys it. His mother indicated that John’s employment is on a permanent part-time basis and that it is not supported employment. That is, John attends and performs his job independently within a very supportive group of colleagues. He works Monday to Friday on a roster system and is “very loyal” to his employer. John’s mother did disclose that she had hoped that this job might present an opportunity for an apprenticeship as a chef; however, this has not occurred. She acknowledged that this goal may have been too ambitious and because John is so content in his current role, she is happy just to see him continue in it.

From the perspective of a 23-year-old-man, John’s material wellbeing is very high for a young man with autism and, arguably, high for any young man of his age. Living, working, and managing his finances, albeit with support, are an impressive achievement for any 23-year-old.

Physical Wellbeing. John lives a very physically active life by engaging in work, sporting, and recreational activities. He is also an avid cook and takes great pride in cooking for himself and his brother. He particularly enjoys finding and trying new recipes. These two factors – physical activity and healthy eating combined with a positive routine, indicate positive physical wellbeing for John. One area of concern relating to John’s physical wellbeing is his high heartrate. John’s mother described him as “running pretty hot all the time”, with his resting heart rate measured at around 100 beats per minute. During times of increased anxiety or stress, his heart rate goes much higher and can stay at high rates for a long period of time. It was suggested by McCraty and Shaffer (2015) that an average heartrate for a healthy adult is around 73 beats per minute, and that consistently high heartrates often indicate increased levels of stress or health risk factors. To manage this, John’s mother bought John a Fitbit and encouraged him to use it to monitor his heartrate.

With this strategy, John and his family monitor his heart rate over time so that they can recognise periods of high anxiety or stress for John and implement strategies to reduce it.

Emotional Wellbeing. These periods of high anxiety or stress are recognised as a key factor in John's overall wellbeing, and it is the one QoL domain where some negative outcomes were expressed by both John and his mother. John's mother stated that "emotionally he's well"; however, his "anxieties are ever constant". She went on to stress that "he has developed some pretty potent strategies of managing that [anxiety]" but "also masking that [anxiety]". Masking is a common strategy used by people on the autism spectrum to hide their high levels of stress and anxiety. Unfortunately, masking may inadvertently increase the level of anxiety experienced and is indicated as a risk factor for experiencing high levels of anxiety long term (Hull et al., 2017).

John also indicated that he has experienced times where his anxiety was high, such as when he moved into the unit, and that certain situations – for example, the taxi not arriving result in him getting "all stressed and flustered". He did, however, share the strategies that he has developed for managing his stress and anxiety, such as taking deep breaths and "ringing the taxi company". Higher levels of anxiety are commonly reported for people on the autism spectrum and can have a negative impact on their overall emotional wellbeing (Howlin, 2021; Oakley et al., 2021). Importantly, John's recognition of these high anxiety levels, and his use of specific strategies, act as a protective factor against the negative impacts of stress and anxiety on his emotional wellbeing (Smith et al., 2019).

Despite the concerns about high anxiety and stress, John and his mother expressed his higher, rather than lower, levels of positive emotional wellbeing. Emotional wellbeing is described as relating to happiness, safety and how individuals feel about their lives. John consistently shared a happy, positive outlook on his life across all QoL domains. John's responses were about things that are going well, decisions that he has made and participating, or planning to participate, in activities that he enjoys with friends and family. Even those activities that are normally not considered enjoyable, such as "dishes duty", John spoke about positively. He considers this an “important job” and expressed pride and contentment in doing the dishes.

5.3.4. Social Participation

Interpersonal Relations. John shared that he experiences a very high level of interpersonal relations with both friends and family members. When asked about how he sees his friendships he stated, “Oh, yes, successful”, and John’s mother stated that she has seen “a lot of growth in [his] interpersonal relationships”. John has maintained close friendships from school and has also developed new friendships at the gym. His relationship with his immediate family is very positive and John speaks fondly of his mother, brother, stepfather and father, and his mother articulated that he “has a lovely extended family”. John’s mother also shared that John is developing a “really lovely” relationship with his current support worker, who is a young man just a few years older than John. She stated that she wanted him to “have that other experience if you like” where he gets to hang around and just “do whatever young men that age would do”, as all his friends also have disabilities.

Social Inclusion. John’s social inclusion can also be considered very high. In fact, John’s level of social participation would seem to be very similar to that of his same age peers. Both John and his mother described the many activities in which he participates, including “archery”, “touch footy” and “the gym”. He’ll “jump in a taxi and go to the shops”, “buy a gift for a friend”, have “outings for dinner” or “go to the movies”. His mother stated, “I mean [he] just never stops”.

John appears to show a much higher level of interpersonal relations and social participation for a young man on the autism spectrum than is described in much of the literature. Typically, the social participation QoL domains (see Table 5.1) are where young autistic adults struggle to form relationships and find inclusion within their community (Bishop-Fitzpatrick et al., 2018). For John, this is not the case at all.

The only negative perception about social participation was expressed by John’s mother when she suggested that “real depth in interpersonal relationships may be lacking”. From her nonautistic perspective, she feels that John’s relationships may be on more of a surface level relationship but stated that “they are there for him”.

She does, however, still wonder, “Is this something he looks for at all or exists for him?” This response is typical of nonautistic individuals, and one that was repeated both across the case studies in this research and within the wider research (Bishop-Fitzpatrick et al., 2016; Hong et al., 2016; van Heijst & Geurts, 2015). It has been acknowledged that autistic and nonautistic individuals have differences in how they view interpersonal relationships, the need for these relationships, and what individuals hope to get from their relationships and social interactions. For many autistic people, they are content with a small number of friends with whom they share interests and limited, chosen social interactions (Mattys et al., 2018).

Human and legal rights. From the perspective of QoL, human and legal rights refer to the rights that individuals experience in relation to their privacy, their level of voice and how they are treated. John’s mother spoke hesitantly about John’s level of human and legal rights. While she feels that John’s human and legal rights are well supported “at this point in time”, she expressed concern for what this might look like without “the family there to support him”. This concern has also been captured in previous research, with findings revealing that one of the greatest concerns of the families of people with autism is what would happen if they were not present to ensure that the autistic individual’s rights are met (Taylor et al., 2019).

John expressed a much simpler, but very relevant, point on this topic. He stated, “Don’t be afraid to ask for help, because help is needed”. The high levels of emotional wellbeing, interpersonal relations, and self-determination experienced by John place him in a position where he is “comfortable, [and] confident” to state what he wants and to ask for help if needed.

5.3.5. Independence

Personal Development. Throughout the interview, both John and his mother repeatedly reported high levels of independence for John in his everyday life, and this has been strongly supported by the personal development that John has experienced since leaving high school. John’s personal development is related to the other QoL areas already discussed – work, independent living, managing money, interpersonal relations, and social inclusion – which in turn lead to positive emotional wellbeing and self-determination. John is strongly encouraged to focus on personal development opportunities by his family, such as completing his Certificates I and II in Hospitality and participating in community activities such as touch football and archery. However, he also makes choices about those activities that he would rather not complete. For example, it is John's choice not to get his driver's licence, instead focusing on learning to use public transport effectively to meet his needs. John telephones, books, and pays for his taxi use and is confident in finding and using the right bus service for where he wants to go. John's mother stated early in the interview that he is "doing more than I anticipated he may have been doing at this point in time". She expressed her delight in the amount of progress that John has made since leaving school, and her pride in his achievements is evident.

Self-determination. Most choices and decisions in John's life are made by himself, with the support of his family. Throughout the interview, John repeatedly used the word "I" as he spoke about his QoL domains. This indicated that, from John's perspective, he is the key person who make choices and plans for, and enacts, decisions across the important areas of his life. Examples of this included, "I can go anywhere", "I ring and book a time", "Pick the things I do every day", "Something I can do" and "That's my opinion". Importantly, John's self-determination relates not only to the autonomy that he has in making choices and decisions, but also to the level of competence that he experiences in his everyday life (Baker et al., 2021; Ryan & Deci, 2017). John talked about what "I" do to be able to live independently. For example, "I make my own meals. I get them from recipe books and that", and "That's something I can do; I just take deep breaths".

John's mother supported his assertions that he makes his own choices and decisions across most areas of his life, with the comment that "There's nothing to indicate that there's something he's yearning for and doesn't feel he has". She did, however, qualify this with the comments that "he works hard to please people", and that you can "just wind him up and off he goes". Thus, while his mother acknowledged that John appears to experience self-determination, she did still express some concerns that he may not be living the exact life that he wants, and that his self-determination could stem more from an acceptance of the routines and structure that exist. Although John's mother expressed concern that this may reduce his level of autonomy and self-determination, Ryan and Deci (2017, 2020) indicated that the internalisation of socially accepted routines and structures can still result in high levels of autonomy being experienced if done so through volitional choice by the individual.

5.4. Anne

5.4.1. Introduction

Eighteen-year-old Anne lives with her mother, father and two sisters. Anne is the middle child with an older sister, Helen, and a younger sister, Samantha. All three girls have a diagnosis of autism. Anne was the first of the girls to receive an autism diagnosis, although her original diagnosis at the age of six was selective mutism. After her initial diagnosis, Anne's difficulties were investigated further and soon after, in Year 1, she was given an autism diagnosis. Anne is the youngest of the participants in the research study and, for her, the transition from school to post-school is in the beginning phase. At the time of the interview, late 2020, Anne had just graduated from a large regional city secondary school and was preparing to start university early the following year. Anne will be studying a Bachelor of Arts majoring in History at her local university.

Anne and Helen chose to be interviewed together with their mother present. Anne and Helen are very strong supports for each other and decided that they were much more comfortable being interviewed together. Anne and Helen's mother acted as an advocate while the girls were being interviewed and was interviewed separately about both girls afterwards. The AAGST (Ashburner, Jones, et al., 2019a) visual cards were used throughout the interview to prompt both Anne and Helen to respond to the QoL domains that were important to them. Anne presented as a well-spoken, articulate young lady; however, she did display high levels of anxiety, through the quivering of her voice and the repeated gripping and twisting of her hands and jumper throughout the interview. Despite this anxiety, Anne was keen to answer all questions and advocated strongly for her personal experiences at school and what this has meant for her.

5.4.2. Quality of Life Domains

Anne summed up her overall QoL with the comment, “Just little steps at the moment”. Anne recognises the current transition from high school to life after school and university as a key period in her life. Rather than feeling that she has or has not achieved good QoL across the domains, she is feeling both anticipation and apprehension about the very different experiences that she is going to have over the next couple of years, and about how these experiences might “work out” for her.

5.4.3. Wellbeing

Material and Physical Wellbeing. The areas of wellbeing that are working well for Anne include both her physical and her material wellbeing. As mentioned above, Anne lives with her parents and siblings in a safe and comfortable environment. Like many young people planning to attend university, staying in the family home offers Anne stability in her living environment, while undertaking the new experiences of university. Anne did mention that “Ultimately, like Helen, I’d like to go overseas and work in a different country”, but for now she is happy to remain in the family home. Anne is working on a part-time basis cleaning “at the same hotel where Mum works at”, and, while she is enjoying the experience of work and earning money, Anne admitted that this is not what she wants to do forever. She also expressed some concerns about her ability to manage the money that she earns, stating, “I do not trust myself with money at all”.

Emotional Wellbeing. Emotional wellbeing is an area of concern for Anne and her family. As discussed in the introduction, Anne presented at the interview displaying high levels of anxiety, and she spoke openly about the emotional difficulties that she had experienced prior to completing school, particularly in the final two years. She stated, “I’ve been through hell with school”, “I became depressed” and “my emotions were all over the place” as a result. She described her main focus in Years 11 and 12 as “Just school [academics], get out”. It is not uncommon for autistic adolescents to struggle emotionally during the final years of school, and to need time to recuperate once school is finished. Cribb et al. (2019) found that young people on the autism spectrum often find school extremely stressful, and this has certainly been the case with Anne.

Now that she has finished school, Anne went on to say, “I’m just trying to de-stress from this year”, and that “as soon as school finished, I love it”. She admitted that she is taking it one day at a time by reading, watching movies, and working. Despite the negative emotional wellbeing that she experienced in her last years of school; Anne displayed a positive outlook about moving forward into the new phase of her life by claiming that “I have a little hope that it might be better”. In post-interview conversations with me, Anne’s mother reported that Anne is “Enjoying her time at university and doing very well in self-advocating with her lecturers and peers”.

5.4.4. Social Participation

Interpersonal Relations. Anne also stated that she is looking forward to using her transition to post-school life to “get out more into the community”, and “improve on my social skills”. Anne stated that she has a good group of friends from school, and she is happy that “some of my friends are also going to Uni”, although she did admit that her friends are not doing the same program as her and that she will just have to “wait and see” if the friendships are maintained. Anne still felt that it will be “beneficial for me to get onto the campus and talk to people”, and she was confident that she would not have “much trouble with going to Uni and talking with people”. Anne was also happy to talk about intimate relationships and stated that “I don’t really have any trouble with relationships”. While she is not currently looking for a serious intimate relationship, she is confident that, when she wants an intimate relationship, she will be able to find and maintain this.

Social Inclusion. Other than going to work and planning to go to university, Anne and her mother did not mention any social activities that Anne does outside the family unit. This, however, may be because Anne has only recently graduated from high school, and she is still navigating her transition from school to post-school. It is also likely to be a result of the high levels of stress and anxiety experienced by Anne during school, and her need to take time to recuperate (see also Oakley et al., 2021).

5.4.5. Independence

Personal Development. Anne identified "asking for help" as a key area that she needs to work on during this transition from school to post-school life. "Asking for help. Me and Helen struggle with this both … We struggle with asking for help." Anne acknowledged that the need to ask for help and to advocate for herself is something that will be needed to ensure that she is able to choose her own path and to take part in the activities that she chooses in the future. Having experienced some setbacks in her quest to do this throughout secondary school, Anne is certainly displaying emerging skills in this area.

Self-determination. The level of independence experienced by Anne has been largely in relation to her school experiences, although she has started to work towards some goals since leaving school. During school, Anne felt that her level of self-determination was limited, as indicated in the comment, "I didn't feel like I had much control over anything at school", and she made clear links between this experience and what she now needs to learn as she transitions to university. Anne described two key examples of where her ability to make the necessary decisions for her own wellbeing had been hindered by the school environment. The first example related to Anne's choice about what she would study at university and what career path she travelled after school. Anne described how she told school staff, "I really want to do history. I want to make it a career" and was told, "History is a (forgive my language) piss poor career. Why would you want to do that? It's better to go into nursing." Anne stated that "I was pigeonholed into doing something I didn't want to do [nursing]", and that she was pushed to do subjects that she did not enjoy or do well at. When she approached the school, Anne was not given any options to move to subjects more suitable for her: "I tried going to teachers and saying, 'Look, it's just not working for me. What can I do?', but they just said 'We don't know. Just deal with it'." Anne described how she failed nearly all the assignments in one subject, and that this had a serious negative impact on her self-confidence and her overall wellbeing during school.

The second area where Anne felt that she had experienced poor levels of self-determination was in relation to targeted bullying directed at her by another student. Anne spoke clearly about the effect that this had on her: "At this time, my emotions were all over the place. I was sick all the time. Mum knows about this, but I was making up excuses not to go to school." Despite these significant impacts on her wellbeing, Anne felt that she was not supported or allowed to make decisions that would have benefited her wellbeing. She was told to “Just walk away”, but, as Anne stated, “Of course, I can’t just walk away all of the time”, especially not when she was in class. Anne’s mother supported this when she spoke about trying to have Anne’s classes changed so that she did not have to face the person bullying her. This was addressed as “not an option” by the school. Both examples discussed by Anne and her mother indicated that self-determination and self-advocacy were not encouraged in the school environment. This final example is particularly concerning as bullying has been consistently found to have significant impacts on the self-determination and wellbeing experienced by students on the autism spectrum (Adams et al., 2016; Autism Spectrum Australia [ASPECT], 2013). Furthermore, the impact of bullying can last into adulthood.

Despite facing these difficulties and the lack of encouragement for self-determination, Anne showed that she is developing the skills necessary to make decisions and to advocate on her own behalf. As discussed previously, Anne has enrolled in the Bachelor of Arts majoring in History. She talked about making this decision towards the end of Year 12 with the support of her family: “I think it was my love for it, and mum and dad just talking to me”. Anne was able to work through the pressure that she had felt from the school to go into nursing to make the decision to follow her interests. Throughout the interview, Anne also often referred to instances where she advocated for herself, such as “going to the teachers”, and “even trying to talk to the school-based police officer” in relation to the bullying that she had experienced. Anne’s mother supported this with the comment that “Anne has had more success with advocating for herself”, and that “I think it’s a confidence thing and being taught how to do it through psychology because she’s had psychological support throughout her entire schooling”.

5.5. Helen

5.5.1. Introduction

Helen is 22 years old and transitioned from a large regional city secondary school to post-school options just over four years ago. Helen is currently living in the family home with her mother, father and two sisters (all three girls have an autism diagnosis). Helen is the older sister of Anne (see participant 5.4 Anne). As mentioned in Anne’s case study, Helen had always experienced difficulties at school; however, her mother and father were unsure what was causing these difficulties and how to support her effectively. It was when Anne was diagnosed with autism in early primary school that the girls’ parents began to understand Helen’s difficulties. Helen’s mother describes the “lightning bolt” moment after Anne’s diagnosis when she realised why the oldest of their three girls, Helen, had struggled for so long at school and in social situations. Helen received her autism diagnosis soon after Anne.

As discussed in Anne’s case, Helen and Anne chose to be interviewed together with their mother present. Anne and Helen’s mother acted as an advocate for the two girls during their interview and was then interviewed separately afterwards. The AAGST (Ashburner, Jones, et al., 2019a) visual cards were used throughout the interview to allow both girls to choose the important topics about which they wanted to talk. Helen used these cards throughout the interview, often referring to them by nodding or pointing to a particular card as she discussed specific topics. Helen appeared very calm and comfortable throughout the interview and articulated her responses quietly but firmly. It was clear throughout the interview that Helen’s calming presence supported Anne to be able to contribute as effectively as she did. When questions were asked, Helen typically responded first, with Anne providing her feelings on the topic after Helen.

5.5.2. Quality of Life Domains

QoL for Helen has been changeable since completing school. Initially, Helen was relieved to have finished with school. She describes her time at school as “horrible”, and “as soon as school finished, I loved it”; thus, the move to post-school was initially felt to be a positive one. Unfortunately for Helen, the negative experience at school was then re-experienced as she moved into post-school employment. Her initial employment after school as a casual aged care worker “went horribly” and exacerbated the poor emotional wellbeing that she had experienced at school. As a result, Helen and her mother describe her life over the last couple of years as “just in the house”. Helen did not experience positive wellbeing across any QoL domains for a significant part of her post-school transition. Fortunately, owing to high levels of family support and finding the right outside support, Helen is now moving into a more positive time of her life where she is starting to regain her sense of wellbeing, social participation, and independence

5.5.3. Wellbeing

Material and Physical Wellbeing. As with her sister Anne, Helen experiences positive material and physical wellbeing where she currently lives with her family in the family home. While Helen did state that she would like to move out, in particular "traveling and going overseas", for now she is content to stay at home and to use the opportunity to improve her QoL and circumstances before travelling overseas after the impacts of Covid have reduced. Helen stated "I've been saving for a while now. It's just really sorting out my passport now and making a proper plan for myself, maybe learning a bit of the language." Although saving has become more difficult as she is no longer working, Helen has put most of her energy into her plans to travel overseas and to visit her online friend in Romania.

Emotional Wellbeing. When discussing what is going well for her and what she is working on, Helen cited "Confidence, definitely. Health and my interests." This comment indicates that Helen has been experiencing poorer QoL in these areas for an extended period. Helen described her emotional wellbeing as "Highs and lows. Some days I'll be fine, absolutely peachy, and then other days it's a complete low, just pure anxiety and stress." She stated that "doctors' appointments especially make me nervous", but mostly "it doesn't have to be anything, it just ticks over and that's it". This poor emotional wellbeing is described by Helen and her mother as starting during school and as being exacerbated post-school with negative employment experiences.

After school, Helen "went to TAFE [Technical and Further Education] and did a couple of courses in aged care", and then got her "first proper job" in aged care. Regrettably, this was not a positive experience. Helen describes how "Being in that environment it was just hard to catch on. They didn't explain things very well." Helen's mother supported this by saying,

> She was signed up with – It was one of the employment agencies that specialise in helping people with disabilities. They were supposed to come into the workplace, assess it, make recommendations for Helen. None of that

> ever happened. Helen was constantly getting into trouble for being too slow. She was really, really good with the elderly; they loved her. They would think that she was kind and gentle and all that, which was wonderful, but she was always in trouble for being too slow.

Helen went on to say, “They didn’t really take into account how I would be in that workplace”, and “It made me more and more anxious and not want to go to work. I’d feel sick before going to work, which is not fun.” Eventually, “they stopped giving me hours”. Being unsupported by adult services is a common experience shared by many autistic adults. Furthermore, the experience of negative emotional wellbeing and social withdrawal is often associated with this paucity of support (Cribb et al., 2019; Goldfarb et al., 2021).

Helen and her mother talked about this experience being part of the catalyst for her withdrawal from life and being “just in the house”. Recent developments in understanding autistic adult outcomes suggest that adults with autism often experience autistic burnout during the transition to adulthood where they experience a “mismatch of expectations and abilities without adequate supports” (Raymaker et al., 2020, p. 140). For Helen, this mismatch was evident in her first work experiences and, as is common for autistic adults who experience burnout, it resulted in negative impacts on her health, capacity for independent living and overall QoL. Helen’s description of her “just in the house” fits with the autistic burnout description, which is “characterised by pervasive, long-term exhaustion, loss of function, and reduced tolerance to stimulus” (Raymaker et al., 2020, p. 140). Typically, autistic burnout results in the adult being unable to participate in most everyday activities and needing an extended period of rest to recover. Again, this is supported by Helen’s statements, “I’ve just been working on myself since then really”, and “Confidence, definitely. Health and my interests.”

Another key aspect linking Helen’s transition experiences to the experience of autistic burnout was provided by her mother. She described Helen as being “very good at social masking”. With Helen in particular, “They’d say, ‘How are you going Helen?’ and her response every time was, ‘I’m fine.’ She wasn’t.” Social masking is defined as “(consciously or unconsciously) compensating for and/or masking difficulties in social and interpersonal situations” (Lai et al., 2017, p. 693), and is considered a common experience for people with autism as they engage in a nonautistic world (Cage & Troxell-Whitman, 2019; Hull et al., 2017). Studies to date support a correlation between high levels of social masking and negative mental health such as increased levels of stress, social overload, anxiety, and depression (Cage & Troxell-Whitman, 2019; Hull et al., 2017; Lai et al., 2017). Additionally, social masking is considered a key contributor to autistic burnout (Mantzalas et al., 2021; Raymaker et al., 2020). Thus, Helen's use of social masking may have contributed to her negative experiences of emotional wellbeing both during her school years and during her transition to post-school options.

Despite the difficulties that she has experienced, Helen is beginning to develop a greater level of understanding of her own emotional needs and is starting to build strategies to support a greater level of positive emotional wellbeing. Helen stated, "As soon as I started working with my OT [Occupational therapist], I built up strategies. That's really been a help, a huge help." She talked openly about "working on herself" and using strategies to develop more confidence in herself. Specifically, Helen has realised that focusing on her interests is a good way to support emotional wellbeing: "Art is my big interest; I've been working on that". Howlin (2021) shared the importance of autistic individuals focusing on what they enjoy and are good at. Helen has also been working on setting up a good routine for her days: "I have my own routine and that helps a lot", and "I have fun with that. That makes me feel good."

5.5.4. Social Participation

Interpersonal Relations. Helen's mother stated that "Helen had quite a sizable group of friends" at school, and Helen herself described her friendships at school with the comment "Yes, it was great". Sadly, "The friends that I had in high school, and then after high school, I don't talk to them anymore. That just fell off the edge. It's no longer there." Helen and her mother went on to describe that "Helen's friends started going out to nightclubs, drinking a lot, and partying and all that sort of thing". Helen stated that "I tried to be [a part of it], but it was really, really hard". She described how the noise of the nightclubs and too many people were overwhelming and just "too much". These difficulties were also described by young autistic adults in research conducted by Mattys et al. (2018). This, combined with the difficulties that she faced in the workplace, resulted in Helen's being "just in the house" and severely limited the number of social interactions in which she engaged (see also Mazurek, 2014).

Social Inclusion. Fortunately, Helen had experienced a positive turn in her social participation since starting with her OT. "My OT, she's helping me with socialising and whatnot", and "The occupational therapy has helped me [to] get out into the world. It's boosted how I feel about everything, being more confident and comfortable with things." Helen described how "We're setting up a Dungeons and Dragons group. It's actually her son that's setting it up really because he's the one that's really into it. She's invited me along. He's got his friends, and it's all … Yes." Helen also talked about feeling more of a sense of belonging to the autistic community. She felt that it is good to be "around other people that understand", because "people like myself, people on the spectrum, don't know how to go about it, don't know how to be in a relationship really" (see also Morrison et al., 2020).

Throughout both the positive and the negative social experiences, Helen has maintained her online friendship with her friend in Romania for over three years. Many young people on the autism spectrum consider online friendships to be easier to engage in, while fulfilling the need for relatedness (Cameron et al., 2021; Ryan et al., 2021). It has been this friendship that has provided the impetus for Helen to want to travel overseas. She spoke excitedly about her plans to move to Romania and stated that "I'd love to stay, really. I think Australia's a 'Been there, done that' sort of thing."

5.5.5. Independence

Personal Development. Independence for Helen can be seen through both positive and negative lenses. Since leaving school Helen has been able to obtain her driver's licence, complete courses at TAFE and gain employment. These are all activities that are considered a normal part of transition from school to adulthood (Arnett, 2014), and to the outside world appear to be successful indicators of independence. This description of Helen's life, however, is not a true indication of the level of personal development or self-determination that she has experienced. Each area where she has achieved perceived success has used a significant amount of emotional energy and been achieved by Helen through social masking. That is, Helen was working hard to achieve what she thought that she should, without any alignment to areas where she experienced autonomy, competence, or relatedness (Ryan & Deci, 2017). This misalignment resulted in an overall negative QoL for Helen, despite the appearance of independence.

A relevant example of this is employment. Helen did not experience autonomy, competence, or a sense of connectedness with her employment. Consequently, Helen's employment led to negative, rather than positive, QoL outcomes (Ryan & Deci, 2017). Helen's mother stated,

> I think had she got extra support at school, being able to make informed choices about her future and what she wanted to do, she wouldn't have gone to TAFE. Certainly not to do that. She might've gone and done an art subject or something like that at TAFE rather than university, but she was … and this was probably partly my fault. I said to her, 'You finished high school; what are you going to do?' I think she just chose that because she was told that there's lots of jobs in that area … 'You'll get a job'.

In the end, choosing the career path that would "get a job" resulted in Helen not having a job, withdrawing from social interactions, and experiencing a poorer QoL.

Self-determination. As discussed in relation to wellbeing, a key factor that appears to have impacted on Helen's ability to experience positive personal development and self-determination is the way that she presents to the outside world. As described by Helen's mother, "Helen doesn't look like she has a disability. She certainly doesn't act like she has a disability. She was just like any other teenager to look at her and the way she acted unless you really got to know her." This was further supported by Helen when she commented,

> I had said to the manager there, 'I've got autism,' or 'I've got Asperger's syndrome'. She sort of waved it off, like, 'Oh, yes, my daughters have that.' They didn't really take into account how I would be in that workplace.

Thus, Helen used the strategies available to her to appear like she was coping in the workplace, social masking, or camouflaging. Cage and Toxell-Whitman (2019) found that many autistic women use social masking for conventional reasons such as functioning in educational or work contexts; however, the use of social masking has the potential to reduce the understanding and support offered to the individual in those same contexts. Consequently, this increases the stress and social overload experienced, and in turn reduces the level of wellbeing experienced across the QoL domains. According to self-determination theory (SDT), reduced QoL in turn reduces the level of self-determination experienced by the individual (Ryan & Deci, 2017). Thus, Helen's presentation and perceived capability, with no true understanding of her experience by her employer or the employment agency, resulted in limited self-determination across all three basic psychological needs of autonomy, competence, and relatedness.

Fortunately, the high level of understanding shown by Helen and her family has allowed Helen to start the recovery process, and to begin to improve her overall wellbeing and to experience self-determination in her life. This is evidenced in comments where Helen described what she has been working on and what her goals for the future are: "Art is my big interest; I've been working on that", "Definitely travelling and going overseas" and "I've always wanted to go to Europe. I'd love to live there." She has moved away from the idea of "getting a job" and instead is focusing on the areas where she experiences high levels of self-determination.

5.6. Frank

5.6.1. Introduction

Frank is 34 years old and lives with his mother and stepfather in a small town just outside a large regional city in southeast Queensland. Frank currently volunteers in a local Aged Care facility and hopes soon to start paid work at the same facility. Outside work, Frank engages in a very active supported community engagement and social participation program that is funded through the National Disability Insurance Scheme (NDIS). As a child, Frank attended a small regional town primary school, and although he had not yet received a diagnosis, required high levels of support while at school. He was diagnosed as being on the autism spectrum when he was 12 years old. Frank's mother explained,

> I knew when he was younger, and I kept taking him, month after month, to different specialists because he had splinter groups, you could see it, but they

> really couldn't put a label on him. They came up with Asperger's, finally, that was when he was 12. It's only even now that they're saying the word 'autism'.

After receiving the diagnosis and moving to high school, Frank was placed in a special education program at a large regional city secondary school.

Interviews were conducted separately with Frank and with his mother and stepfather. Frank's mother and stepfather were interviewed together first, and Frank was interviewed separately after his parents' interview. Frank's interview was conducted with no advocate present, although his mother and stepfather were in another room close by. He did not use the AAGST visual cards in the interview. Frank presented as a very animated and engaging young man, who possessed high levels of verbal language skills. He spoke openly about all the QoL domains, and he shared some very personal information throughout the interview.

5.6.2. Quality of Life Domains

Frank's QoL across all the domains presented as being very conflicted. While he is living in a safe, secure environment and receives high levels of support across all the QoL domains, at the same time he has experienced many negative situations that have significantly impacted on his wellbeing, social participation, and levels of independence. Throughout the interview, Frank expressed his understanding and appreciation of the support that he receives, while again simultaneously expressing his dissatisfaction with the limited independence that he perceives himself as having. This contradiction was also expressed by Frank's mother and stepfather as they described how they work hard to provide Frank with opportunities to make choices and to engage in positive activities, while at the same time struggling to protect Frank from the serious negative consequences resulting from some of his decisions (see also Cribb et al., 2019; Taylor et al., 2019). Thus, it is difficult to determine whether Frank considered his overall QoL as positive or negative. Rather, he seemed to exist within a constant state of conflict between the positive and the negative aspects of his QoL.

During the interview, Frank initially commented,

> Well, now that I’ve finished school, for many years, I didn’t know how to do anything, to tell the truth. Because I was at different disability companies, and all they pretty much wanted me to do is to colour in and play at the park, and pretty much brainwashed me into being a dribbler.

He continued by stating, “Because I’ve gone through the school of hard knocks in life, I’m not happy there. I’ve made some very shameful decisions and some very poor decisions. I am very embarrassed of it.” Frank shared that “after school I went silly and made a few wrong choices in there” and that most of what he has learned since school was “just from general life skills, through bannings, just through general life events that happened”. Sadly, Frank finished this discussion with the comment, “I wish I was born another time so I could restart life, go back 10 years and just make different choices.”

Frank’s parents were slightly more positive in their assessment of Frank’s overall QoL, “In the rest of the stuff, like he’s got his routine. He’s got support workers. He’s been travel training to Brisbane. He’s got his exercise classes he does. He does the volunteer work. He’s out and about.” They went on to share that Frank’s academic skills are “Poor. He did get through to Grade 12, but he’s probably Grade 3; Grade 4 is probably his level. He’s probably equivalent to about a 12-year-old in some things”, and as a result “He’s had to have somebody prompting and supporting him. If he didn’t have that, he would be all at sea”. Frank’s mother stated,

> I’ve been very proactive with Frank. As much as people say that I’m a bit silly, I say, ‘Look, you give him an opportunity. If he fails it, it’s fine, but let him fail at it and work out what he can do and can’t do’.

She feels that “It’s just giving them the opportunity. A lot of them don’t have the opportunity because they’re not given any.” Frank’s mother and stepfather see their role as giving Frank as many opportunities as possible.

5.6.3. Wellbeing

Material Wellbeing. As described above, Frank currently lives with his mother and stepfather in their home, and, while he stated, “I have a lot of independence here”, he also shared,

> I don’t want to stay here forever … I would like to get my own place, a little two-bedroom place and live umm … I don’t want to go to SIL [Supported Independent Living] or residential. I don’t want that. I just want … I’d like to live like a normal person, having my own place. I’ve got my car, eventually I’d like to upgrade and get a better car, but first I’d like to move out of home. I’d get a place of my own, manage my own finances.

Frank did admit, however, that while he washes and irons his own clothes, he will only “Cook when I have to and clean when I have to, not when I want to. Cooking to me is more of a chore than a hobby.” Again, these comments were supported by Frank’s parents when they stated that, “He can do stuff. If he can get away with it or doesn’t want to do something he won’t.”

Despite this, Frank’s parents know that Frank wants to move out of their home and live on his own and his mother stated,

> We’ve been working towards that [independent living]. It’s just, it’s a bit like just breaking that … you can do it. He’d probably ring you a million times a day, but he could do it with support. I think he would enjoy doing that. It’s just finding the right place.

However, both Frank’s mother and stepfather stressed the importance of Frank being provided with support if living on his own were to be realised, “He must have support. He could never live on his own and manage himself.” They went on to share that he requires prompting “all the time, constant, constant”, and they gave examples such as “Turning things off, closing doors, shutting things, things like that. He doesn’t remember to do things.” Additionally, “Unfortunately, Frank’s number skills aren’t good so if you say to him ‘Put that in the microwave,’ and he just picks any number that he thinks. Like 35 minutes and then he’ll walk away.” This description of limited daily living skills, as described by Frank’s parents, has been shown to impact seriously on the ability of young adults to live independently (Baker et al., 2021; Duncan et al., 2022). They also shared the importance of Frank’s routine being maintained so that he could manage independent living, even with support,

> He could do it; it’s just that he would need that support to say, ‘Right, Frank, have you remembered this/ Remembered that?’ Just prompting. We’ve got different setups, watches, and different alarms and things that he’ll do …

> remember to take medication so he can self-medicate. He does mess up every so often but most of that we've got that down pat. We've got systems but don't take him out of routine.

As with many young people on the autism spectrum, Frank's routine is a critical support for his autonomy and self-determination (see also Milton & Sims, 2016).

Another consideration in considering Frank's ability to live independently is his difficulty with managing money. Frank's parents stated that Frank has very limited skills with budgeting: "He's not good with money. He's not good with finance." As a result, they feel that he will always need support to manage his money, a common finding for many young autistic adults (Cheak-Zamora, Teti, Peters, et al., 2017). Frank's mother shared that,

> I have tried absolutely every strategy in 34 years that I've known, even those suggested by psychologists [to teach Frank how to manage money]. It's just one of those things; he needs assistance with it. You can't give him even a cent. If you give him $10, he'll spend $20. If you give him money to go and get his snacks, he'll go and get a dream catcher and an electric toothbrush and come back with no snacks.

Additionally, Frank's mother stated that, while she has not been able to teach Frank how to manage his money, he has learned strategies to "work around them, because he's not silly". She described how he will

> Go and buy a pack of M&Ms and take $75 out of the bank … He thinks that if he takes that then I'm not going to see there's a cash withdrawal. Then he goes and buys the cars and the toys.

Frank's mother described how Frank "Buys huge amounts of cars and planes and has no concept … no concept of, 'How can you afford that?'" His stepfather commented that if not supported he'd "have a house full of toys but nothing to eat".

Owing to the conflict with money Frank's parents now have Frank's money managed by the Public Trustee of Queensland. Frank is aware of this situation and is not happy about it, "I don't want to put the Public Trustee, but … it's just a matter of bite the bullet, take one for the team and do as you're told." He reiterated several times that "Eventually, I would like to leave the Public Trustee, because I'm not very fond of the Public Trustee, honestly", although he did admit that "there are skills I need to learn [to manage my money]". Additionally, Frank commented that "Like I get my pension, but it's not enough. For the lifestyle I would like, I need more financial support." For Frank, there seems to be a level of conflict between the level of autonomy that he would like to have with his finances, and the level of competence that he has in being able to manage his finances effectively (Cheak-Zamora, Teti, Peters, et al., 2017). This conflict, in turn, impacts on how he viewed the support provided by his parents in this area. While Frank would like to have full control of his own money and resents the controls put in place by his parents, Frank's parents feel that allowing him full control of his money would result in an even poorer QoL for Frank in the long term. Thus, the difficulties in maintaining Frank's wellbeing and safety while also supporting his autonomy were a key concern shared by his parents. This concern has been shared by many parents throughout research on the outcomes for young autistic adults (Cribb et al., 2019; Hirvikoski & Blomqvist, 2015; Taylor et al., 2019).

An area of Frank's QoL that is improving for him is work. Frank is currently volunteering at a local Aged Care facility and both Frank and his parents are confident that this volunteer role will soon become a paid position. Frank's parents discussed that,

> He's done his Certificate III in Individual Support. That was pushing a lot of support where support workers had to help him [to] go through that, but he did it and he's currently volunteering at an Aged Care facility three days a week. That's going really well. He's found that little niche.

However, his mother stated,

> He has support to do that volunteer work. They monitor him so if his language … when I say language it's not swearing … It's just that Frank, he might say something really inappropriate. His choice of subjects [is] not good … I don't think he's capable of doing it on his own.

This was a concern for Frank's mother as she shared,

> It looks like they may give him paid work at the Aged Care facility as a lifestyle officer. It would be interesting to see how it goes without that

> support worker. That's the one I don't know. He can do it with the support worker standing there while he's doing it, but he's got them as confidence. Take that confidence away, I don't know. [I think] He'll panic.

Frank, however, displayed a high level of confidence in his ability to work in the Aged Care industry,

> Even my boss, she knows I have got it in me to become more than just a volunteer. My trainer at the Aged Care facility, she's been training me up, and she's also been seeing a massive change in my morale.

He commented that "I really am grateful I'm in aged care and I want to continue working there. What I intend to do is become a lifestyle officer, go and get a career." Frank stated that, "I'm doing what I want to do now in aged care", and "I find it so much more easy to interact with and get along with [the elderly]". Frank also felt that "Who knows, if I have gotten more confidence in myself, I might be able to do a job that's more higher than lifestyle officer." Again, Frank's perception of his competence with the job is very different from his parents' perception. As with finances, Frank believes that he is capable of working with complete autonomy, while his parents believe that support is required for Frank to be effective in the workplace long term (see also Dreaver et al., 2020; Lorenz et al., 2016).

Physical Wellbeing. Frank described himself as "Not a very sporty person" but shared that "I do exercise classes. I enjoy that." He went on to describe how "They are working. At the moment, my legs are quite sore, but I thought, 'Well, my legs are sore, that means the treatment is working'. Sometimes my arms are the same. This just means the muscles are tearing and growing. That's all it means." Although Frank focused on the physical wellbeing component of exercise classes, Frank's mother emphasised the importance of exercise for his emotional wellbeing:

> We have a plan in place, but I prefer not to use medication. If he can do it himself naturally, as in calming himself down, [with] exercise. We've got him going to a gym up the road here, three times a week, so he's doing that.

Emotional Wellbeing. Emotional wellbeing was a key discussion point regarding Frank's overall wellbeing, although it was Frank's parents who primarily discussed this. They discussed emotional wellbeing across three main areas: self-regulation and consequences; conflict and lying; and anxiety and strategies. Frank's parents described how, "That's the biggest problem. Consequences. He doesn't have a good understanding of self-regulation or the consequences of his actions." Frank's parents used many examples to illustrate this lack of understanding across all QoL domains, including finances, the topic of conversations that he chooses, relationships with others, social expectations, personal development, and everyday decisions that involve his own personal goals and wellbeing. All are common areas where young autistic adults have been shown to struggle with self-regulation (Dijkhuis et al., 2017). Furthermore, Frank's parents described how Frank does not understand others' emotions, or appropriate ways to respond to them. An example provided by Frank's stepfather was, "A few years ago, when Frank's mother had her transplant, I came home and said, 'It doesn't look like your mum's going to get past the weekend, the doctors have said that'. He said, 'Do I get her phone?'" Frank's mother added, "Then, when I didn't die, I made it, he said, 'Does that mean I didn't get the mobile phone?'" A key characteristic of many autistic people is that they struggle to understand their own emotions as well as the emotions of others (Huggins et al., 2021). This difficulty has been shown to create significant misunderstanding regarding the autistic person's capacity to consider others point of view or to respond in socially appropriate ways during emotionally difficult situations (Huggins et al., 2021). The descriptions provided by Frank and his parents regarding his emotional responses indicate that Frank does experience difficulties with self-awareness and self-regulation of his emotions and actions.

The topic of conflict and lying was also linked to Frank's emotional wellbeing. Frank's mother stated, "He hates conflict; he'll say anything to avoid conflict". Frank's stepfather added that "He lies. Tells you lots and lots of lies, probably I would say 75% of his conversation would be lies", although he did acknowledge that "It's probably not a lie to him. It's his own interpretation of what he believes." Frank's mother supported this statement: "He'll get a little bit of information … We nicknamed him 'Distortion Pedal' … because he adds his little bit to it and makes it whistle." Even though Frank did not discuss his response to conflict during his interview, his parent's responses indicated that Frank chooses not to engage with difficult situations such as conflict. Furthermore, Frank has developed some socially inappropriate strategies, such as lying, to avoid dealing with difficult emotions and situations.

Anxiety was the third area discussed in relation to Frank's emotional wellbeing. Frank's mother described how

> He gets anxious if anything goes wrong, he gets really anxious and uptight and then everything's gone … It can be a roller coaster, especially if a girl comes into the picture. That can be a really bad thing, as in it's great that he has the company, but he's not emotionally mature enough to handle it, is probably how I'm going to put it. For instance, they say, 'I'm turning up at three o'clock'. By two o'clock he's really frantic, panicking, panicking, panicking. By 3:00, if they're not here, he will lose it. When I say 'lose it', [it's] his emotions, he just gets so upset and anxious and starts swinging his arms. Then, if he has a break-up, then it's about two years in therapy. He basically has a breakdown.

Frank's family have engaged support to help him to deal with high anxiety levels.

> He used to do walking to try and lower his anxiety levels. When it's really bad, that's when he goes to the psychiatrist and then they'll medicate to try and get him down to a reasonable level. We have a plan in place, but I prefer not to use medication, if he can do it himself naturally, as in calming himself down, [with] exercise.

"Before he would just walk all day. All day, back and forth, back and forth, back and forth." Frank did mention the strategy of walking to reduce his anxiety levels; however, he also shared that,

> What I like to do is I have in the past gone for walks around town but stopped doing that quite a lot because the police used to pull me over because they used to think I was casing people's houses or looking into people's places.

Frank's stepfather also mentioned this difficulty with Frank using walking as a calming strategy for his anxiety: "He's been pulled up by the police a number of times. He's probably just blinking and looking into space, but they see him looking and they say, 'He's looking in that house'. That's their perception, not Frank's perception." Gibbs and Haas (2020) and Railey et al. (2020) described how negative interactions often result from police not having an awareness of autistic characteristics and thus misinterpreting behaviours. Thus, Frank has started using the strategies of “isolation”, and “Loud music, he likes loud headbanging music on every night. He turns the music up and air drums. He’s broken two beds by jumping up and down on them.”

5.6.4. Social Participation

Interpersonal Relations. When discussing interpersonal relations Frank commented,

> Yes, I do find it very hard. Yes, very hard. I wish honestly, I could just … I honestly wish I was born in the ‘90s. I wish I was born another time just so I could restart life, go back 10 years and just make different choices.

Frank described many difficulties that he experiences with interpersonal relations, including his current relationship with his girlfriend, difficulties with friendships and the problems that he experiences trying to use social media to develop and maintain friendships. Frank’s parents also discussed each of these topics.

Frank started the conversation on relationships talking about his girlfriend, “I have a girlfriend whose name is Jenny”, and “We can be on and off sometimes, just depending on her mood”. He went on to share,

> Yes, honestly with my girlfriend, Jenny, she chops and changes her mind all the time, but really, I just want to be with a person who’s stable and steady and wants to be with me. Because the relationships I’m having now, they’re just on-off ones, and really, it’s pathetic … With Jenny, it’s just always another thing. Right now, she’s starting to flicker again, which I think I expected anyway, but I’d like to find something that is stable and is solid.

Frank’s mother reinforced this when she talked about Frank’s girlfriend, stating, “She has anxiety, she met Frank and could only stay with him for a couple of hours, then went back home. He smothers girls.” She went on to say, “Frank can’t differentiate between what you should look for in a relationship and I call ‘desperate and dateless’; he fits into that category. He’s not emotionally mature enough to handle close relationships.” The difficulties with intimate relationships discussed by

Frank and his parents are common experiences for many autistic adults (Cheak-Zamora et al., 2019; Hancock et al., 2020). Although some young adults choose to avoid relationships because of these difficulties, others, like Frank, continue to seek relationships and to experience negative outcomes.

Friendships are proving to be equally difficult for Frank to develop and maintain. Frank's parents commented,

> He's got a couple of friendships. There's been one girl, she's been really nice to him. She has a major disability, but she can see through all the stuff; she pulls him into line every so often, but he doesn't see her a lot. That's about it.

Frank, on the other hand, emphasised, "I find it almost impossible to make friends". Furthermore, he rated one of the more negative aspects of his QoL as "the choice of friends I have or shouldn't have". He described one family, "There are some friends just down the road from me. They aren't exactly the people who I thought they were. Just lies and deceit and things." He shared that, "I thought I had become part of the family", but "it hasn't worked, and I wish to hell I hadn't met them". Frank's parents used the same family to highlight Frank's vulnerability to social manipulation:

> It's the same with [the family]. The manipulation, he can't see it. He's so naïve. He thinks, 'Oh, that's great. They're friends.' He believes in whatever they say, no matter what they say. They'll just rip him for whatever they can, and he just can't see it.

Furthermore, "He'll fall out with them. Then all of a sudden, because there's nobody else, he'll go back to them." Developing and maintaining friendships are often described as a core difficulty for people on the autism spectrum (Crompton et al., 2020). Frank displays many of the core differences in how he perceives and understands others, resulting in poor social and relationship experiences. For Frank, the success of his relationships depends on the understanding that the other person has about Frank's experience of social interactions and on her or his willingness to accept and support these differences (Morrison et al., 2020; Sasson et al., 2017).

Frank also discussed his use of social media to try to meet people and to develop friendships. This, however, has also not been a positive experience for Frank: "I've got Facebook, I've got Instagram, I've got Snapchat as well. But, to meet people on Facebook, I've learnt, it doesn't go very far." Frank did show insight into some of the difficulties that he experiences with using Facebook when he stated,

> Sometimes it can be good; sometimes it can be bad. I do find I can talk to more people with it, but there's also sometimes I might say something on Facebook and people might laugh, and I'm like 'I shouldn't have posted that'.

Frank's mother, on the other hand, stated,

> Probably the worst thing I ever did was [to] give him a mobile phone because that's where the trouble started. That's where the social issues started … The problem is he's over 18. It's his choice. But he's getting himself into a lot of trouble [using social media], it's his naivety … He gets scammed all the time and it's just … they're targets.

The use of the word "targets" may seem extreme; however, research indicates that autistic people are often at increased risk of experiencing victimisation in social interactions (Weiss & Fardella, 2018).

Social Inclusion. The majority of Frank's social inclusion is supported through his community access and participation program funded through the NDIS. Frank has high levels of social inclusion because, as his mother stated, "I'm keeping him busy because, if I don't, he will sit in that room on his phone all the time." Frank talked openly about the social inclusion that he experiences as he views it as a positive aspect of his QoL:

> I also enjoy going to Brisbane. I go every weekend. I often go with a lady who is my long-time friend and support worker. She is a lovely lady, and she's teaching me a lot, because she knows a lot about Brisbane.

Frank is also supported to participate in volunteer work, attend a gym and participate in general community activities such as shopping and going for coffee. When I asked Frank if there were any groups related to his interests in model cars and trains, he commented, "No, it's mainly elderly people who're retired. I'm the only young one there and they go, 'Look at this young whipper snapper. Here he comes.' Then they sit there and then they go, 'Back in our day …'." It is unfortunate that Frank is not able to find a community group with whom he feels comfortable sharing his interests in model cars and trains as finding natural support and inclusion around strengths and interests can be a positive social experience for autistic adults (Cameron et al., 2021).

Human and Legal Rights. A key aspect of Frank's QoL revolves around negative experiences regarding his human and legal rights, particularly in relation to social inclusion. Two stories were shared by both Frank and his parents that illuminate the difficulties that Frank has experienced in this area. The first relates to Frank's strategy for reducing his anxiety, as described previously. Frank's parents described how, "He used to do walking to try and lower his anxiety levels. He would just walk all day. All day, back and forth, back and forth, back and forth." Furthermore, Frank not only walks but runs as well: "He's sprinting. In the door, out the door and around the town as well." This behaviour has led to negative interactions with the police, "He's been stopped by the police because he looks suspicious. Because he's sprinting. And then the way he stands and looks. He wouldn't do anyone any harm, but it's the way he stands and looks." "Probably just blinking and looking into space, but they see him looking and they say, 'He's looking in that house'." This limited understanding by the police regarding the strategy that Frank uses to deal with anxiety has resulted in Frank having to stop using the strategy (see 5.6.3 Emotional Wellbeing). Frank described how, "What I like to do is I have in the past gone for walks around town but stopped doing that quite a lot because the police used to pull me over because they used to think I was casing people's houses or looking into people's places".

The second incident relating to legal rights involved Frank being banned for entering his local McDonalds store. Frank commented that, "I also still have a ban at McDonald's here because the girls there decided to set me up and take me for a fool. I was their fall guy. I still am banned to this day." The ban was put into place because Frank was perceived to be stalking the young female staff of McDonalds. Frank stated, "It was misunderstood. The police were called." Importantly, the ban has not only impacted on his ability to go to McDonalds, but also Frank feels that, "Ever since the banning at McDonalds, most people stay away from me", and that "the more I try, the more people go, 'Oh, Frank's doing this, Frank's doing that'." He feels that this mistake has had a lasting impact on his overall QoL and social inclusion within the local community. Frank believes that "I've changed. I'm not that person anymore." He feels that "When everyone knows you, they're always watching you. Even if I was allowed back in there, they'd be watching me." He added, "People always make me [out] to be a creep and a stalker. I have admitted that I had … Sometimes, I do stalk, but I don't mean to. It just happens." Frank's parents reinforced this with the comment, "Frank doesn't realise he's a stalker. He wouldn't know about if there's consequences or boundaries and things like that, you see."

Both incidents, as well as other stories shared, presented significant concerns for Frank's parents in relation to Frank's wellbeing, social inclusion, and independence. The first concern is the need to ensure that Frank understands how to navigate social experiences in a socially appropriate way that reduces the chances and opportunities for misunderstandings and police involvement (Gibbs & Haas, 2020; Railey et al., 2020). The second concern, however, is the situations that Frank's limited social understanding can result in, in terms of his own vulnerability. Frank's parents spoke often throughout the interview about Frank's naivety, unconditional trust and acceptance, and vulnerability to being scammed and/or mistreated, or being set up take a fall. Frank's stepfather stated, "That could happen. That could happen with the wrong person. It might be somebody that sets him up for the fall."

5.6.5. Independence

Personal Development. Frank primarily focused on his volunteer work when he discussed his personal development. A key goal for Frank is to move into paid work with aged care and to work his way up to become a lifestyle officer:

> I think I need to do a course of some sort to help me [to] further my education, apply myself more at work. I think I really need to focus and develop more skills at work. Yes, I'm happy where I'm going, but I want to further my skills. Actually, I want to climb the ranks and become an officer and actually work on things.

Frank has already completed a Certificate III in Individual Support, and described how he would like to continue learning in this area:

> I want to take this opportunity to further educate myself in studies in tertiary education and see where that leads me to in my career, hopefully, aged care … If I could do something at university, in aged care, I think I could flourish there. I could get a better car, a better job, I could move out to a better place. I could do better things. All around, the keyword is ‘better’.

While Frank believes that “I have the capabilities” to achieve this, Frank’s parents emphasised the significant amount of support required for Frank to complete his Certificate III. Thus, although they do not want to prevent Frank from following his goals, they are considering how best to provide the support that he would need to succeed in further study.

Across all the other domains of QoL, Frank’s parents have implemented strategies to help him to continue to learn and to move towards greater independence. This has been primarily done through NDIS funding to employ support workers to support Frank with learning independent living skills such as shopping, cooking, and cleaning. An example of Frank’s learning skills to improve his independence is having his driver’s licence. Ghanouni et al. (2021) described the importance of autistic adults having transportation options and the increased opportunities that this can provide. Frank’s mother also felt that this was important; however, she described how,

> When I dared to say that I’m going to make sure he gets a licence because that could increase his chances of a job, they all said, ‘You are absolutely crazy.’ I went through the path of going to the OT … We had an OT assessment on him to see could he safely do it. He can’t handle a manual, but he can handle an automatic.

Frank also sees having his licence as helpful for his independence: “It means I can just go and do whatever I want … within reason of course, within the route.” This is another example where Frank displays a level of contradiction, or tension, between his desire for complete independence, and his knowing that he has limitations attached to it. He acknowledged the freedom that driving gave him, while at the same time, admitted that he was limited in where he could go. Frank’s parents, however, were adamant that,

> It’s a safety issue, so he doesn’t go out of the city limits. He’s only allowed … he has to have somebody in the car if he goes any further. He can’t concentrate long enough to go any distance. If he was to drive further, then his concentration would lapse.

Self-determination. As expected, given the level of tension across multiple QoL domains, this tension is evident in Frank’s perception of his self-determination. While Frank indicated throughout the interview that, “at the moment, I am quite happy with the choices I get to make”, he also made many statements that indicated that he would like to have more autonomy across many areas of his life. For example, “I’d like to live like a normal person”, “Look, it’s my life”, and “I’d like to move somewhere and start afresh”. Frank expressed that he feels, as he gets older, that this need for self-determination becomes even more important to him:

> Well, if I don’t make my run now, I’m never going to be able to make my run. I’ll be sitting home, playing with my toys, as you probably heard, and wanting mummy to do everything … Look, I’m 35 years of age, I shouldn’t have to say, ‘Mum, can I have my money for this? Mum, can I have my money for that?’ I should be able to say, ‘Look, I have a job, I can just go to my account, run this through, get the money that I need and go and buy whatever it is that I require’ … That’s what I’d like to do.

While Frank expressed this need for greater autonomy, he also acknowledged the importance of the support provided by his family, particularly his mother: “Mum supports me a lot, and she’s seen friends come and go. I’m worried about, how am I going to look after myself in the future? Where am I going to be?” He also indicated that,

> Sometimes I do worry about my future, what’s going to happen to me after mum dies. I do worry about that quite a lot. I keep thinking, ‘How am I going to keep the lifestyle I have now without mum?’

This concern is something that features throughout Frank’s interview (see also Mattys et al., 2018), and has most likely increased as a result of his mother’s past serious illness and surgery. Even though Frank may not have expressed his concern and worry for his mother in a way that the rest of his family understood, it appears to be an experience that had a lasting impact on him and his perception of his future.

Frank's mother acknowledged the tension between Frank and his desired level of autonomy, and her need to ensure that he has somewhere appropriate to live and is safe. She explained how she tries to ensure that he has as much choice as possible with the goals he is working towards: "He'll choose, and he'll tell me what he wants and that's his goals." However, she also shared that,

> You must have a plan B. We had strategies in place if anything went wrong. Frank doesn't like the strategies but as I said, 'Come up with a different option.' The only option would be a residential you see, or in a SIL. That was the option if anything happened to me.

This goes against Frank's goal to

> Just to get my own place, whether it be local or in Brisbane, in the future, long term, I'd like to move to the coast. In my 50s … in the long-term future, I'd like to move to the coast because I'm a little bit over here personally.

Frank and his family have already faced the unenviable task of having to make decisions about what care and support Frank could access if he did not have the current family support provided, and this is a task that they are still facing. Planning for a future without family support is a common difficulty encountered by families of adults who experience disability (Ghanouni et al., 2021; Mattys et al., 2018).

5.7. Paul

5.7.1. Introduction

Paul is 38 years old and was diagnosed with autism as a young child. He lives with his father in a small regional town in South-East Queensland. Sadly, Paul's mother passed away when he was very young, and, while Paul talks fondly about his mum and what they used to do together, his dad has been the key support person throughout his schooling and adult life. The interview with Paul was organised through the local community autism support group. I visited the support group during a group meeting and talked about my research and my search for participants. While Paul's father was not able to be interviewed, Paul was very keen to take part in the research and volunteered to be interviewed that same evening. He was interviewed with no advocate present and did not use the AAGST visual cards (Ashburner, Jones, et al., 2019a), as he was comfortable talking to me about his life.

After the interview was completed, Paul was also keen to socialise and chat, and he engaged in many conversations with other members of the support group and myself, the interviewer, throughout the evening.

5.7.2. Quality of Life Domains

From Paul's perspective, he presented as having a good QoL across all domains. Overall, Paul talked about the positive aspects of his wellbeing, social participation, and independence to a greater extent than he talked about the difficulties that he experiences. There were, however, two areas in which Paul experiences less positive QoL. The first relates to the high levels of anxiety that Paul experiences, and the second is the result of Paul's not being able to continue studying climatology and work in the climatology/meteorology area as he would have loved to do. Nevertheless, Paul showed high levels of resilience as he has developed and uses a range of strategies to address both areas.

5.7.3. Wellbeing

Material Wellbeing. Paul works for a local company that makes beehives, making the beehives and all their components. He has been working for this company on a casual basis for five years and stated that he "likes his work", and "gets enough work". When he discussed his work, Paul talked about what he has learned about bees, the effects that the weather has on their honey production, and the components of the beehives that keep the bees safe from pests. He showed a positive level of interest in his workplace and appeared to be content with the work that he does.

Budgeting was something that Paul referred to often throughout the interview. He admitted that "It started off a bit funny, but now it makes it pretty good", referring to initial difficulties that he had with budgeting his money. However, living with his dad means that he is able to share household bills and chores with his dad, and Paul indicated that he is now able to make plans with his money, stating "I'm saving … I'm trying to save more money, my work money, so I'll have money when this Covid thing blows over. I can go on a cruise somewhere."

Physical Wellbeing. Healthy diet and exercise are the keys factors that Paul discussed when talking about his physical wellbeing. When referring to cooking meals, he commented that they are "You know, just basic, a few fish fingers and a couple of Steamfresh. I buy those packets of Steamfresh veggies from Woolworths and always drop a couple of packets in there. It makes a good meal." He also talked about the various physical activities, such as archery, that he participates in with his peers from the autism support group. Paul also commented that "I take a herb … a couple of herbs for it [his anxiety]", indicating that he is aware of the importance of diet and exercise for both his physical and his mental health.

Emotional Wellbeing. Throughout the interview, Paul spoke primarily about the positive things in his life, those that bring him happiness and a sense of wellbeing. These positive feelings were indicated across all the QoL domains, including wellbeing, social participation, and independence. Interestingly, there appears to be a strong connection between Paul's strengths and interest in weather and all the QoL domains, including his emotional wellbeing. Throughout the interview, Paul's conversation showed that his work with the local social media weather group allows him to experience both feelings of competence and a strong connection with his community. This, in turn, leads to a high perception of wellbeing for Paul (Ryan & Deci, 2017).

Although his overall emotional wellbeing is positive, Paul did indicate that he can experience high levels of anxiety. He stated, "I do have anxiety, like sometimes I'll get … I'll feel a bit flustered", and "I used to get panic attacks". Although high levels of anxiety are found to be a common characteristic for people on the autism spectrum, having strategies and support for dealing with this anxiety can reduce the negative impact on overall QoL (First et al., 2016; Spain et al., 2018). When discussing the levels of anxiety that he experiences, Paul was asked about whom he talked to about his anxiety or if there were anyone he could go to when he experienced high levels of anxiety. His reply was, "I don't know about that." Rather than having people who support him, Paul stated that "You just have to battle it out and it comes good again." He described how "Sometimes they were that bad, I just had to go home and have a lie down just to let everything settle down." This shows a high level of resilience with Paul being able to acknowledge the anxiety that he experiences, but also know that his anxiety will reduce once he has given himself time to rest.

Overall, Paul's level of emotional wellbeing seemed to be underpinned by a high level of resilience and gratitude for what he does have in his life. Paul acknowledged and accepted both what he does and does not have in his life and worked hard to be able to include those things that are important to him. For example, while Paul stated that he would have liked to have been able to work in the climatology/meteorology industry, he still spoke positively about the job that he does have making beehives. At the same time, he uses his work on the local social media weather group to continue engaging with his strengths and interests outside his work (Grove et al., 2018).

5.7.4. Social Participation

Interpersonal Relations. Interpersonal relations and social inclusion are also QoL domains that were perceived positively by Paul. Throughout the interview, he referred often to those relationships that he does have in the community through comments such as "I catch up with a friend that I … that I used to work with for a coffee every now and again", and "That's why I jumped on Facebook, just to link up with a lot of my old school friends. Yeah, I talk to them on my Facebook I'd say a bit." He also shared his perceived high level of connection with his community as evidenced through his statement, "Yeah, I'll say 'Hello' if I see somebody. If I'm walking down to get the paper or somewhere and I see somebody on the footpath, I'll say 'G'day' to them." This was also evident through the observed positive interactions between Paul and the other members of the autism support group.

Social Inclusion. Paul's main avenue for inclusion in the local community is through the local social media weather group. Paul stated that, "We've got more than 6000 [members]" of the Facebook page. The positive perception that Paul has about the Facebook page was supported strongly by members of the autism support group who spoke to me about it during the meeting. One gentleman, who is a local farmer, indicated how much he values Paul's weather predictions. He stated that he makes business/farming decisions, whether to plant crops or to sell off cattle, based on

Paul's weather predictions. He stated that, "He's more right than any of those other guys on TV."

5.7.5. Independence

Personal Development. Self-determination and personal development are, again, very closely connected for Paul. He indicated through his conversations that he makes most decisions for himself and uses opportunities to learn new things to support these decisions. Much of Paul's interview centred around his love of weather and the local social media weather group. The development of this page was a decision that Paul made himself: "Yeah, yeah. When [Cyclone] Oswald come through, there wasn't much in the way of weather stuff for the local area. So, me and my friend got together, and we set up the Facebook group." However, Paul also indicated that he had well-developed computing skills to support this decision: "I went out to TAFE. I did it for a couple of years. I've done a Certificate III and IV in Information Technology." The connection between personal development and self-determination was also emphasised by Paul when he talked about his desire to "go on a cruise somewhere", "maybe to the South Sea Islands", and when he stated that he was working on getting better with his budget so that he can "save more money" to go on the holiday.

Self-determination. Paul had also had some negative experiences in the areas of self-determination and personal development. He talked about his uncle who "Got me doing some stuff at the University of Southern Queensland [USQ] when he was there. There was a climatology course down there." However, Paul also shared that "I found it a bit hard to do", because "I'm used to the face-to-face classroom, and it was online". When asked if there were any supports offered in terms of helping him to be successful in the course, his response was "No." Paul also expressed his desire to work in the climatology/meteorology industry: "Yeah, I probably would have liked to have worked in the Bureau of Meteorology." However, because he was not able to complete the study, this was not a career that was available to Paul. As indicated throughout the interview, however, rather than letting this impact negatively on his love of weather, Paul found another way to include his area of strength and interest in his life and community through the Facebook page. Thus, Paul's interest in weather and the fact that he has found a way to use this strength within his local community have contributed significantly to all areas of his QoL, wellbeing, social participation, and independence (Grove et al., 2018).

5.8. Tamara

5.8.1. Introduction

Tamara is 20 years old and lives with her family in the family home. Her family consists of mum, dad and two younger sisters. Tamara is the only child in her family with a diagnosis of autism and was diagnosed at the age of 11. The family live in a small regional town approximately one hour's drive from the nearest regional city in southern Queensland. They have always lived in the same small regional town and consequently know many people in the community and have strong links to the school that Tamara attended.

The interview was conducted with Tamara and her mother separately. Initially, both were sitting together but, when I asked Tamara's mother, "How would you describe Tamara's QoL since finishing school?", her mother suggested that it may be best for Tamara to come back after her interview. As is discussed in detail below, this was because Tamara's mother felt that "This year hasn't been great; it was better when she was working" and did not want to speak negatively in front of Tamara. Throughout the interview, Tamara's mother appeared to be quite nervous and admitted at the beginning of the interview that this was the case. Conversely, Tamara did not appear nervous at all during her interview. Rather, she presented as very eager to share her story, and she spoke at length and in detail about each topic. Tamara presented as a highly verbal young lady who thought deeply about each question and wanted to answer the questions in "just the right way". This was indicated throughout her interview with frequent pauses, incomplete sentences, and changes in the direction of her answer. Tamara completed the interview with no advocate present and chose to use the AAGST visuals (Ashburner, Jones, et al., 2019a) throughout the interview. While in the interview, Tamara commented that she finds it easier to think and respond appropriately when she can see a visual representation of what she is talking about (see also Harrington et al., 2013).

5.8.2. Quality of Life Domains

At the time of the interview, Tamara had been out of school for approximately 18 months. During this time, she had experienced both positive and negative aspects across QoL domains. A significant influence on Tamara's QoL was that she had been "let go" from her job working in childcare a few months before the interview. Both Tamara and her mother indicated this to be a strong influencing factor on how things were progressing for Tamara and her family post-school. Tamara's unemployment, and the need to look for another job, had put additional pressure and stress not only on Tamara, but also on her family. On the other hand, her mother did suggest that post-school life is less stressful overall for Tamara: "I think it's a lot better because I think school was very stressful and she puts high expectations on herself. She struggled with school; she struggled academically."

5.8.3. Wellbeing

Material Wellbeing. Materially, Tamara has a very safe and secure position. Living with her family in the family home means that Tamara has a safe and comfortable place to live while she looks for a job. She has ample money to spend on the things that she enjoys and has her own car that she is learning to drive. The focus of Tamara's conversation on her material wellbeing revolved around her being "let go from her job" and needing to find a new job. She stated, "I've been here for about three months now without a job", "I'm really missing it, and it's something I'm very passionate about." Tamara went on to indicate that "I really want to continue working in childcare. It is very important to me [getting a job]." Tamara's mother supported these statements: "Childcare was something Tamara discovered she enjoyed, and she wanted to do. She would come home and be all enthusiastic about what she'd done [at work]."

Adding pressure to the situation, Tamara and her mother indicated that she was not receiving any support for her job searching, "I'm doing it all myself [searching for a job]." This lack of support is the result of limited options with employment agencies in the small regional town. While there are employment agencies in town that do support job searchers, Tamara's mother indicated that they are "Not very helpful and it is better just to do it yourself." Additionally, none of the agencies offers disability specific support and thus they do not always consider what it means to be on the autism spectrum when searching for employment (see also Cribb et al., 2019). Instead, Tamara is relying on her connections to the community, and the people in it, to look for work. She stated, “I’ve gotten two interviews” and described how she did work experience at both childcare centres where she had the interviews, while studying childcare through a school-based traineeship. Thus, she knew most of the staff, and they knew her and how she worked. Tamara hoped that this would help in her quest to find employment in the local childcare industry: “I think this one’s going to be more successful because they already know me.” Despite the success of getting to the interview stage, Tamara admitted that “Searching for a job is not fun.” However, she acknowledged the importance of getting a new job quickly (see also Goldfarb et al., 2021) because “I see my job, like, childcare as something that I want to work long term; it’s something I’m passionate about. I want to make it my career.”

Tamara did discuss wanting to move out of home “one day”; however, she admitted that it would not happen until she had a job and could save some money. “I’d really want to move closer to Jonathon’s [her ex-boyfriend’s] family, his family is, actually … They’re both pastors and they’re really supportive and they understand me having … [they] understand ASD.” Tamara felt that she had the life skills to move out of home and live in her own house: “I did actually learn those skills at school”, and “I think they did okay [describing the school’s teaching of life skills that supported her transition to independent living].” However, Tamara’s mother stated, “I think she needs to learn more life skills before moving out on her own.” She commented that, “Tamara doesn’t do a lot of the household chores”, although she is “doing more now that she’s not working”.

Physical Wellbeing. While Tamara’s physical wellbeing is generally positive, both Tamara and her mother mentioned that she does have physical and verbal tics. Her mother stated, “Tamara has a tic, a shoulder twitch and some verbal tics as well”, while Tamara indicated that “When I’m feeling stressed, my shoulder moves”. These tics do not impact negatively on Tamara’s physical wellbeing; however, they are physical characteristics that can impact negatively on her emotional wellbeing. Tamara’s mother indicated that, “We just laugh about it. Not at her, but … you know.” Tamara herself talked openly about her shoulder tic, providing a demonstration of what it “looks like” in the interview, while at the same time making comments that suggested that she can be quite self-conscious about it: “All the kids will notice those weird quirks, whereas younger kids they don’t pick up on those as easily”, and “I think that’s why I connect really well with the kids. Because they just accept you for who you are.”

Emotional Wellbeing. As with Tamara’s material and physical wellbeing, her overall emotional wellbeing appeared to be very positive. While both Tamara and her mother did speak about some of the difficulties that she had faced recently, there was also a lot of conversation around how she felt about situations and the strategies that she used to deal with these difficulties. Behind each comment was a high level of self-awareness, self-determination, and resilience. For example, while she admitted that losing her job had taken a toll on her emotional wellbeing, at the same time Tamara had engaged independently and willingly in searching for a new job, used her connections with her community to do so, and showed a positive, confident outlook regarding her chances of being offered one of the jobs. This was further supported when she discussed how her boyfriend had “broken up with her” earlier in the year. Again, Tamara acknowledged that this was a difficult time, while at the same time she talked openly about the important role that he had played in her social life throughout school, and how she is happy to “just be friends if that’s what he needs right now”. Tamara’s emotional wellbeing appeared to be very closely tied to her high levels of self-determination. That is, she had shown that she is able to accept the difficulties that she experienced and to use her high levels of autonomy, competence, and relatedness to work through each situation in a positive, competent way (Ryan & Deci, 2017).

Tamara also talked about the many strategies and support structures that she used to enhance her emotional wellbeing:

> Drawing I found, in the last three months, has helped me [to] find something to make me happy. It helps me to have space where I can just set my mind free. I [also] bought myself a journal and I like to do poetry and write lyrics and things like that.

Tamara linked these strategies with the work that she was doing in childcare: “It’s because of the children that I actually felt more inspired to really allow myself to get creative.” She also referred to her friends and family and the important role that they play in supporting her: “I think it’s important to have people that you can rely on and people to bounce off of and have your support group, people that you can go to when you need support” (see also Mattys et al., 2018).

Tamara did admit, however, that “I do struggle with feeling like people don’t understand me. Especially at home, I feel misunderstood.” This was supported by her mother, who stated, ‘She thinks we don’t understand her. It can be really difficult. She can be very mean at times.” These difficulties and experiences were discussed by Tamara and her mother under two key autism specific areas. Her mother described how “Tamara has difficulty transitioning mid-activity” and that, “if she’s focused on something, she has to finish it”. This characteristic is very common for people on the autism spectrum and relates to one of the diagnostic categories in the Diagnostic Statistics Manual 5 [DSM5] (American Psychiatric Association, 2013). The DSM5 (American Psychiatric Association, 2013) states that people with autism will display a preference for routine and structure in their behaviours, and typically have difficulty in transitioning between routine or activities. Thus, Tamara’s insistence on completing an activity before moving on would seem to be closely aligned to her diagnosis of autism.

Similarly, Tamara described the social communication difficulties that are a part of autism and how these present for her. She talked about how “Everything makes sense in my head but then when I put it out there, how I’m feeling, I can’t explain it.” Later she also described how “Everything’s visual in my head and so I’m having to put English words to what’s going on there.” It was at this point in the interview that Tamara pointed to the AAGST visuals and said, “That’s why this is useful.” She went on to state “I don’t know how to express my emotions as well as someone else might.” As with her transitioning behaviour, Tamara’s experience of social communication difficulties is very similar to how other autistic people have described their experience of social communication (Kim, 2019).

5.8.4. Social Participation

Interpersonal Relations. Interpersonal relations are a QoL domain where Tamara described some difficulties; however, at the same time, she showed high levels of understanding and self-determination. Tamara's mother indicated that "It's hard, especially when Tamara's … she's quite shy and doesn't want to put herself out there", and "It's really hard for her to make friends when people don't get her." Tamara supported this statement but shared a different way of thinking about it: "I like having limited friends because … I don't know. I'm happy to talk to people but keeping a friend is a different thing." She went on to say, "I see an acquaintance as somebody who knows who you are, but not who you are deeply, kind of thing", and "A true friend to me, is somebody who is supportive and I'm willing to support them, they're willing to support me." Her final point of the discussion around friends was that "I really look for people who … it goes both ways, kind of thing." This level of insight about friendships, what they are for and why they are important is an area of strength for Tamara. In this area, it could be suggested that Tamara demonstrated a greater level of understanding about the make-up of genuine interpersonal relations than is typically described in the autistic population (Huggins et al., 2021; Maitland et al., 2021).

There are two key friends in Tamara's life that about whom she talked often throughout the interview: Samantha and Jonathon. Samantha was first mentioned by Tamara's mother: "She's had a friend since she's been a baby." Tamara's mother went on describe how she and Tamara's father and Samantha's parents have been friends for years and how the two girls, Tamara and Samantha, were close in age. The girls basically grew up together and have always been close, but "Samantha was home-schooled, so that made it difficult". Tamara also talked about Samantha; however, she presented a slightly different view: "I'm very happy that I have somebody who is not in the school circle. Somebody who has just stuck by me for all these years, and I've stuck by her for all these years." Rather, Tamara views her friendship with Samantha as providing her with an opportunity to meet people outside the school environment: "She's given me opportunities … like she invited me to the Church group." This friendship had become even more important to Tamara since she finished school as it is a friendship that existed outside the school environment. Thus, Tamara was able to maintain a friendship that did not alter considerably after school.

Jonathon was described by Tamara as her boyfriend throughout school; however, “we broke up at the beginning of this year when he moved away”, although she was very quick to state that “we’re still good friends”. Tamara talked about how’

> I did not like him when I first met him. My first impression of him was he’s weird and everyone at school thought that too. I saw that awkward … not knowing that I had the same awkwardness as he did, but I saw his awkward interactions.

However, a teacher at the school suggested that they should get to know each other, because both Tamara and Jonathon are on the autism spectrum. Tamara described how “We started talking and, from that day on, we were just best friends.” She went on to talk about the significant impact that her friendship with Jonathon had had on her life: “He taught me to have a carefree … not to care about what other people think kind of thing”, and “He has also taught me to be more open and understanding towards other people as well.” This experience of finding close connections and understandings with other autistic people has been described by Morrison et al. (2020) as providing improved social relationships and a positive sense of connection. Tamara’s mother, however, felt that the relationship was not always a positive one for Tamara: “Her boyfriend, or friend now, he has Asperger’s too. You’d think he’d be more understanding, but I think he hasn’t really been very understanding.” She continued to share that the break-up, combined with Tamara’s losing her job, had had a big impact on Tamara’s QoL over the last few months: “Everything just came up at the same time.” Despite this, Tamara did share a positive attitude about the break-up, stating that “It’s helped me to take a step back and realise that I was actually shutting other people out and focusing too much on him”, and that “I was more only communicating with my boyfriend for a long time and that was not healthy.” Rather, Tamara stated that “I don’t see this [intimate relationships] as a necessity in life”. She commented that,

> I do want it [her relationship with Jonathon] to lead that way, but I also don’t mind if he decides to go on a different path or something like that, which I don’t want to happen, but that’s up to him and I’m willing to just support that. It’s also okay to have people in your life that you can just be a support to.

Social Inclusion. Tamara has a small number of community groups of which she is a part within her local community. Tamara and her family regularly attend church, and Tamara has been participating in a local church group over the last few years. She described how the church group was “a good way to meet new people”, but also to “stay in touch with people from school” after it finished. It was initially her friend Samantha who introduced Tamara to church group, and, in turn, Tamara also introduced her younger sister to the group. She did, however, talk about how she is not attending church group as regularly anymore as “Now she [her sister] has invited her friends and it kind of feels like it’s her thing now and not mine.”

A key aspect of social inclusion about which Tamara spoke was the social get-togethers that are organised by one of the school’s retired teacher aides: “Now that she’s retired, she’s been doing monthly get-togethers”, and “She’s gotten people who were involved in the enrichment room to come and have lunch together and she wants to have everyone there one day.” Tamara talked about how important this group had become for her, especially since losing her job. She said, “We have been having coffee at least once a week together and that’s really … that’s helped.” She went on to share that the group helps because she feels understood and accepted in the group: “She’s got ASD grandchildren, and her son is also ASD. So, she has a real passion for people like us and getting us somewhere and she understands the social aspect.” For Tamara, this level of understanding and acceptance was very important to her and the social get-togethers are a place where she felt that this occurred (Pellicano et al., 2019).

Human and Legal Rights. Tamara expressed very strong views on her right to choose to share her diagnosis with others or not. Tamara felt that “I want to keep it under the radar as much as I can”, and “I want to have them see me for who I am first because I find that, as soon as someone finds out, they kind of look at me through a different lens”. From Tamara’s perspective, “That’s why I prefer some people not to know because they start to treat you like you have some disability, [while] it’s a disorder.” Regardless of whether the other person treats her differently or not, once they are aware that she has autism, she “feels like they now see me from a different viewpoint and that makes me feel not as respected”, and “I feel not as confident in myself for some reason, like now they know my secret”. However, she also stated that:

> If they ask questions, I'm willing to answer them. When I know people, I'm okay to talk about it, but I prefer not to talk to people about it unless I know them first. But also, I want to keep it to [limited] people until I feel like … I don't think it's necessary for people to know.

Individuals' right to share their experience of autism when, and with whom, they choose to do so, is a very important one (Crompton et al., 2020). For Tamara, this right to choose allows her to manage both how others perceive her and, also how confident and respected she feels in a given context. In terms of sharing her diagnosis in the workplace, this was expressed by Tamara as a key area where she believed that she has the right to choose.

5.8.5. Independence

Personal Development. The two key areas of personal development for Tamara are continuing her studies in childcare and getting her driver's licence. Both areas offer considerable challenges for Tamara; however, she was determined to achieve both. She stated clearly, "I want to continue studying", and "I want to get my diploma". Tamara expressed that "I see my job, like, childcare is something that I want to work long term, it's something that I'm passionate about", and getting her diploma will support this career choice. Yet study is something that can be difficult for Tamara, as her mother stated: "Reading has never come that easy to her, and her writing isn't the best." Tamara is aware of these difficulties, however, and discussed her plans to "approach the Cath Dickson Centre and see if they are able to help me with the diploma". The Cath Dickson Centre is a local support group who supported Tamara to achieve her Certificate in Early Learning. Given that Tamara achieved her Queensland Certificate of Education (QCE) at the end of Year 12, she believed that she had the skills to complete her diploma, even if it required more effort.

Obtaining her driver's licence is the second area where Tamara was working hard to improve her independence. Tamara's mother described Tamara as "quite a nervous driver". Tamara expressed the experience of driving as "There's so much multitasking with driving and when you're new to it and you have a brain that flutters around you don't really … like that's just an extra thing." She did, however, express confidence in her ability to drive, just that she needed no distractions.

Tamara talked about how she looked forward to the day when she can drive by herself so that others are not in the car distracting her. This is one area where Tamara feels that she is “misunderstood”. Because she is on her learner’s permit and must always drive with her parents, and often her siblings, in the car, she described how they talked, pointed things out and asked her questions, while she was trying to concentrate on driving. Tamara described one incident where her family were including her in a conversation and, because she was distracted, she had to “stop quickly” at a stop sign. Her sister’s comment when they arrived was “Maybe you shouldn’t be driving if you can’t focus on more than one thing.” For Tamara, this lack of understanding of her perspective was the reason that she commented, “There was a time where I was going on about how I didn’t feel encouraged. That’s what I meant, like those little things.”

Self-determination. Throughout the interviews with Tamara and her mother, a high level of self-determination was evident for Tamara. Across all the QoL domains, Tamara showed very high levels of autonomy, competence, and relatedness (Ryan & Deci, 2017). Tamara has, with support from family and others, made many choices about what she wanted to do and how she would achieve these goals. Although Tamara’s mother stated that she “struggled academically” at school, Tamara demonstrated the competence and drive to succeed at her school-based traineeship and to complete Year 12. Tamara herself showed great pride when she said “I got my QCE, so … I’m very happy about that!”

It is, however, the area of relatedness where Tamara showed her greatest strengths. Throughout the interview, Tamara demonstrated a significant level of insight into how she thought about and viewed relationships, as well as insight into how her interactions with others impacted on both her and them. The presence of high levels of social and emotional self-awareness, or understanding the feelings and perceptions of others, is a skill that is often considered to be limited in people on the autism spectrum (Huggins et al., 2021). For Tamara, this is certainly not the case. She showed remarkable insight into her, and others’, place within the community and how relationships with them supported her autonomy, competence, and relatedness, thereby, overall providing Tamara with high levels of self-determination.

5.9. Eric

5.9.1. Introduction

Eric is 22 years old and currently living with his mum and stepdad in a regional town in South-East Queensland. He has recently returned to his family home after obtaining a degree in Physics at the Australian National University (ANU) in Canberra. Eric lived away from home in Canberra for four years while he attended university. Upon returning home, Eric has gained employment as a teacher aide at a local school and has also started his postgraduate studies, enrolling in a Masters of Learning and Teaching. Eric is self-diagnosed as a person on the autism spectrum. While Eric describes how he always struggled with the social and communication aspects of life, his success in academics and his ability to develop strategies to compensate for the difficulties that he experienced meant that a potential diagnosis was never considered. It was not until Eric started working in the education sector supporting students with special educational needs that Eric and those around him started to see the connection between his experiences and those of others with autism. Eric stated, “I was mortified when my boss sort of suggested, uh, that I was … that I was on the spectrum”; however, he proceeded to research what it meant to be on the spectrum. After much deliberation and many conversations with his family, Eric has embraced that he is indeed on the spectrum. Eric described this as an ongoing process, stating that “I’m still figuring it out.”

The interview with Eric and his mother was conducted via Zoom. This was the only online interview conducted throughout the research. Eric was present for his mother’s interview but completed his interview on his own. Throughout the interview with Eric’s mother, the close bond between the two was evident, with Eric and his mother joking throughout and sharing differently nuanced versions of the same stories. During Eric’s interview, he showed a great deal of insight into how autism has impacted on him throughout school and beyond, and a keen willingness to share his experiences openly. He did not use the AAGST visual cards during his interview as he was very confident and comfortable speaking about his experiences without visual supports. Eric described how “Interviews are great because I can just talk about myself.” He went on to say that “I get less nervous doing interviews than when I’m paying for $50 of groceries”.

5.9.2. Quality of Life Domains

Eric's mother stated that she thought that Eric

> [v]iews his QoL as good, but that it's tempered. So, living back at home after being away for three years, I think he's found challenging because he developed independence and how he's back under mum and dad's roof and so there's a … there's a challenge for him navigating himself as an adult. But I also think that there are some good things that he's happy about.

She went on to describe how Eric is very comfortable with the person that he is, and thus he does not feel the need to change to suit anyone else, "Eric is unashamedly, Eric." Eric's mother talked often throughout the interview about the gifts that Eric possessed and the benefit that this had had for him. She described Eric as a very "high achieving student", as well as being a "very gifted musician". Furthermore, Eric's mother described how resilient he was when things "get tough".

Eric supported his mother's views about his QoL. Throughout the interview, Eric also talked about the positive aspects of his life, such as his friends – "I have some very good friends", and his work, "So I love what I do. Uh, I really do." He was, however, very quick to state at the beginning of the interview that "Adulting is hard." He stated, "I didn't figure it [the person that he is] out in high school. I didn't figure it out in uni. And I think I'm only just now starting to figure it out." Furthermore, Eric emphasised that, "The person that I appear to be now is not the person I was then." The use of the word "appear" can be viewed as an insight into the significant levels of social masking and compensation techniques that Eric has developed and uses every day to increase his social connections with others and to fit in to the world in which he lives (Cage & Troxell-Whitman, 2019; Hull et al., 2017). These descriptions are elaborated on throughout Eric's case analysis.

5.9.3. Wellbeing

Material Wellbeing. During school Eric attended the National Youth Science Forum at ANU, and from that experience he decided that he wanted to attend ANU once he had completed school. Eric's mother described how her first reaction to this was “Arrgh!”, as she had significant concerns about how they were going to make that work for Eric. However, she went on to say that

> His best mate was at the same school, but then his family moved to Canberra so that family said, Come, come move in with us, you know, we’ve got a spare room.’ And I think, from my perspective, the decision to go to Canberra would not have been as easy had he not had a familiar environment that was just going, ‘Please come and live with us’.

She admitted that “The decision for him to move interstate would not have been as easy had he not had that familiar support.” Eric and his mother describe how this arrangement initially proved beneficial and allowed Eric to move to Canberra and settle into a routine of attending university while ensuring that he experienced comfortable and safe living arrangements.

Eric’s mother shared that “The family that he initially moved in with … that went pear-shaped about six months in, so then we had to find somewhere for Eric to live.” This period proved to be difficult for both Eric and his family. Eric’s mother described how

> It was really hard not being there because I felt like there was no support that he could go to. So, we did spend a lot of time on the phone, and I could … it was really hard to hang up because I knew that the minute I hung up, he was alone again.

Eric stated, “Yeah, I just needed support.” Eric and his mother described how they then had to find another family for him to board with. Eric’s mother summed it up with the comment “It wasn’t just finding a place for him to live because I knew that Eric needed to feel welcomed and supported.” As a result, she admitted to doing “a good proportion of the legwork” from afar because “Eric struggles to phone … to talk on the phone so that is very challenging for him to have to cold call someone.” She also shared that she experienced “a good proportion of the worrying”, at which point Eric interjected with, “I think we split the worrying equally.” While they were able to find another family for Eric to live with, this too only lasted for a year and a half, and they again had to find somewhere for Eric to live. His mother stated, “So I think it started out very glossy, but, by the end, it wasn’t as easy or as affordable as when it started out.” The experience of managing daily living skills while also focusing on studies when attending university can be very difficult for all young people, and often requires significant support from parents and families. However, Anderson et al. (2020) described the increased importance of this support for young people on the spectrum. Furthermore, experience difficulties with non-study related factors have been shown to increase the chances of young autistic adults withdrawing from university study (Cai & Richdale, 2016). Despite this, Eric's mother described how she was "surprised at how well he did when things got tough". She commented that "I felt like his study was really challenging through the time, but he still got really good grades. So, he managed to do it, but it was … I was worried about him." In the end, though, it was Eric's love of what he was doing that allowed him to work through these difficult times. His mother stated that he found the resilience to keep going, "Mainly because he loved what he was studying", and "there was a reason for him to be there and that was what was important" (see also Ward & Webster, 2018).

After he completed his degree, Eric and his mother discussed what he would do next. Eric had the option of staying in Canberra and enrolling in honours; however, he decided to move back to Queensland. Eric told his mother, "I miss being away from my family; I really want to be closer" and admitted that "It also helps that I couldn't afford rent at the time, so I was haemorrhaging money very quickly." Eric's decision to move back to live with his family and to enrol in postgraduate studies had proven to be a positive choice for him. Eric stated that "I love what I do. Uh, I really do." While his mother admitted that moving back home is "a challenge for him navigating himself as an adult", she also found that "I've seen him a lot happier in his study this year because he doesn't have competing pulls on his time and there's less pressure. And I really see Eric happier when he's not under a lot of pressure." Thus, after working through periods of difficulty, Eric's material wellbeing was stabilised at this point in his life. He was living in a stable, comfortable home where he was "welcomed and supported". In turn, this had provided him with the opportunity to focus on the thing that he loved most: studying at university. Reduced stress and focusing on the things that they love have been shown to be supportive of a high QoL for people on the autism spectrum (Grove et al., 2018; Kim, 2019).

Physical Wellbeing. Physical activity is one area of physical wellbeing where Eric admitted that he has little interest in participating: “I have no interest in it [playing sport or being physically active], and I’m not good at it so I … I’ll never do that.” Eric’s mother supported this, saying, “Eric has never enjoyed sport. He is not a sporty person, as much as I tried when he and his brother were little. We tried everything, and it was red crosses in every box.” He did, however, indicate that “I reckon if I applied myself, maybe I could develop to … to actually be able to do it.” Despite not being someone who participates regularly in physical activity, Eric does maintain his health and wellbeing through nutrition. Eric’s mother talked about how the family had become vegan two years ago and that she was worried that Eric was maybe struggling with these food choices. Eric replied to this with “You make it sound like I’m putting up with it. I’m not.” Despite his lack of enjoyment of physical activity, Eric showed awareness of the value of nutrition and presented as having high levels of physical wellbeing.

Emotional Wellbeing. As described above, Eric’s mother indicated that “I really see Eric happier when he’s not under a lot of pressure.” She shared that “When he was in Canberra, he phoned me almost every day without fail. We’d usually have a half-hour conversation. When I didn’t hear from him for a few days, I’d know, everything’s great.” She commented that “It’s not necessarily advice too. I think that Eric processes things externally sometimes, and I’m the safe person for him to do that with.” Eric supported this with the comment, “It [talking to mum] is usually every day.” Eric was very upfront about his emotional wellbeing, stating, “Emotionally, I don’t understand myself because it’s not something that can be compartmentalised. It’s not something that can be deconstructed and … fixed.” He shared that “I didn’t understand any of what I was feeling at that point [during adolescence]”, and that this is something with which he is still grappling. Thus, the support that his mother provided in helping him to “process” his emotions was invaluable.

Emotional wellbeing is not a separate entity that is removed from every other aspect of QoL (Muniandy et al., 2021). Rather, emotional wellbeing is closely tied to all other aspects of a person’s life and experiencing poor QoL in a particular domain can impact on an individual’s emotional wellbeing. For example, poor physical wellbeing may be associated with poor emotional wellbeing, just as poor self-determination is also often associated with poor emotional wellbeing (Ryan et al., 2006). For Eric, his emotional wellbeing is perceived as being attached to the various domains of his life. In relation to his physical and material wellbeing, Eric experienced high levels of emotional wellbeing. His family and friends were very understanding of him, and who he is as a person, and they were supportive of the choices that he made. Similarly, in personal development Eric experienced very high levels of emotional wellbeing. Eric emphasised that "It's really what gets me up in the morning, I think … you know, being able to learn stuff." He has experienced success throughout his studies, both in school and post-school, and so he expressed high levels of confidence and self-esteem: "I absorb information like a sponge" and "particularly for me the benefits of being a polymath is that usually doesn't present any problems because I just am generally good at a lot of things."

The area of social participation, however, is where Eric perceived his emotional wellbeing as being less than ideal. He admitted that he experienced extreme levels of anxiety before and during certain activities. While some of these would be considered very typical, such as "performing on stage", other everyday activities that are a key part of adulthood and self-determination also caused extreme anxiety for Eric. An example of this provided by Eric was, "What's not so good is not having my hair cut in six months because I need to make a phone call to book the appointment and I won't pick up the phone. True story. Had my hair cut a couple of weeks before last, because I finally mustered the willpower to actually phone up and book myself an appointment. I get really bad performance anxiety when making phone calls." These high levels of anxiety around phone calls often resulted in Eric not being able to do things that he needed to do or wanted to do in everyday life or requiring higher than expected levels of support from family. Interestingly, research conducted by Howard and Sedgewick (2021) found that anxiety around phone calls is very common among the autistic population, and that the phone is often the least preferred method of communication.

While general social participation with strangers was an area of extreme difficulty for Eric, interpersonal relationships provided both positive and negative experiences in terms of his emotional wellbeing. Eric stated that "I have some very good friends", but still described how interacting with people in social situations is "Not something that I'm naturally good at." Eric admitted to using a significant amount of camouflaging, social masking, and compensation techniques to manage social situations. Throughout the interview, Eric described in detail (see 5.9.4 social participation) how he managed conversations and the strategies that he had learned to “be social” with his nonautistic peers. Often, the use of camouflaging can result in high levels of stress and exhaustion for autistic individuals (Cage & Troxell-Whitman, 2019), and Eric did suggest that it was “A lot of hard work.” At the same time, Eric admitted that sometimes he just said, “Look, mate, um, I’m not in the mood for talking to new people at the moment.” The fact that Eric understood when he needed time out from social situations and that he was confident enough tell people this was an area of strength for Eric. Thus, high levels of self-awareness and confidence, combined with the protective factors of high intelligence and a supportive environment, allowed Eric to experience overall positive levels of emotional wellbeing, even though he found many everyday aspects of life difficult (see also Huggins et al., 2021).

5.9.4. Social Participation

Interpersonal Relations. Achieving an overall positive QoL relies heavily on achieving autonomy, competence, and relatedness in the areas of social participation (Ryan & Deci, 2017). That is, individuals need to be able to choose the type and level of social participation in their life, have the skills to be able to achieve this, and develop reciprocal relationships that support social participation. Eric acknowledged throughout the interview that he did experience autonomy, competence, and relatedness within this QoL domain, even if his experience were not the same as for his nonautistic peers. While Eric’s mother commented that “Making friends is not something Eric has done, really. He has stuck with one friend from school who is still in the area, and they catch up possibly once every two months”, Eric qualified this with “So mum really downplayed my social circle because she doesn’t think that people I speak to online count.” Eric described how “I have about five good friends”, but he feels, “That’s enough for me. I don’t need to know a lot of people.” So, while Eric may present as not having a wide circle of friends or a busy social calendar, this was a choice with which Eric was happy.

Competence in social interactions was an area where Eric described a great deal of development over the years. Eric explained how as a child he was:

> Not very sociable at all. I wasn't even … I didn't understand … this whole idea of making lots of friends. I didn't get it, because why would you do that? I had no interest in it because I didn't know what that meant.

He went on to elaborate that "The only friends I had were the ones that were given to me, which were, you know, your mum's friend's kids." However, Eric admitted that when he started attending regular school he realised how "lonely" it was without a friendship group (Mazurek, 2014). So, Eric decided that he needed to make friends and went on to detail the strategies that he used to learn this new skill:

> It's funny how closely related public speaking and making friends are. We used to do public speaking as part of home schooling and over time I was able to take this one thing I'd done and kind of use it … in another area.

He stated that "It took me a good year or so, but I started to make friends." Eric now found maintaining his important friendships much easier. He described how "Particularly with my close friends now talking to them doesn't require effort because I've done it enough times that I … I know when they use a particular tone or when there is a particular …" He paused and exclaimed, "Wow, this makes me sound like such a robot!" Although it was clear that Eric had developed very specific and structured ways to communicate and socialise with other people, he also emphasised that:

> It's just muscle memory for the brain. It's not like you're doing a conscious analysis of the conversation to work out. 'Okay, so where's this going?' It just happens automatically. You get to a point where it just becomes second nature.

Despite these obviously highly developed strategies, Eric admitted that he still felt frustration with certain aspects of social interaction:

> I find conversation interesting because I … it can be really tedious when there's all these rules and things. I understand the basic rules of conversation, but there are certain aspects of it that I think are pointless and don't need to exist.

Eric also shared his perceptions and feelings about sexuality and intimate relationships, a very personal aspect of his social participation. Eric described how,

> Uh, as a natural result of puberty, usually, that’s when you start to explore, you know, your sexuality and how you align with things and whatnot, and, for me, that didn’t happen. Basically, that was when I kind of discovered that I was asexual.

Eric admitted that he “didn’t fully understand it at the time”, and stated, “I don’t understand it still at all, but I am coming to terms with it.” When he discussed being asexual, Eric used many statements that indicated that he felt misunderstood and alone with this aspect of his life. He made statements such as “Nobody cares”, “It doesn’t really offend anyone, but at the same time, if there’s so few people [who] fall into that category, there wasn’t any drive for it [research]” and “Nobody seems to understand.” He also expressed significant frustration with the societal response to sexuality: “It’s a great source of irritation for me at how hyper-sexualised our culture is. It’s just shoved in your face all the time. It’s just so alienating.” Eric maintained that “It’s very lonely because nobody fully appreciates what … what that entails. The problem is that very few people actually look for that. I have never found anyone.” Furthermore, he shared that “I’ve had a history of very unpleasant friends … well, unpleasant … very awkward friendships that never went anywhere”, and “I’ve come to the conclusion that it will involve a certain degree of compromise on my part at least.” Eric finished this part of the conversation with the statement, “I wish somebody had told me to give up on chasing girls, because it’s … it’s a trap … and I will never be happy.” The experience of questioning sexual interest, or lack thereof, is again a very common experience for many people on the autism spectrum (Attanasio et al., 2021; Ronis et al., 2021), although, as Eric suggested, this is not a well-researched area and much is unknown about the experience.

Social Inclusion. When asked if Eric participated in any community activities such as sports or if he had any hobbies, he replied, “If it doesn’t require other people.” Eric’s mother expanded on this by saying that Eric has never enjoyed participating in community activities, and that “The only people he sees are us, so my husband and I. My parents, and sometimes his dad, and sometimes his grandparents, his dad’s parents. His brother who lives in Brisbane now, they have a very strong bond.” She stated that “Mainly his community is an online community – World of Warcraft.” Again, Eric interjected with “You make it sound like a stranger on the internet. These are all people who I have met in person and know very, very well", to which his mother replied "Yeah, but it's an online community." Eric and his mother appear to have different ideas about what constitutes a "community". Cameron (2021) found that autistic individuals often experience a positive sense of connection and relatedness with an online community, and that they do not feel the need for face-to-face contact to experience relatedness with another person. Furthermore, differences of perception between parents and young people on the autism spectrum have been found to be common (Hong et al., 2016), with contemporary research indicating significant differences in how autistic and nonautistic people experience social interactions and relationships (Milton, 2012). While Eric and his mother disagreed on this domain, Eric summed up his view of online friendships by stating, "I think if last year [during the Covid pandemic] proved anything it's that you don't have to be immediately next to somebody to keep in touch with them."

One area of social inclusion that Eric described as causing extreme anxiety was making phone calls. Eric explained that "I think it's because I can't see the person on the other end. And there is a lot of information missing when you can't see the person you're talking to." Additionally, Eric feels that

> When it's on the phone, the voice is slightly distorted, so it doesn't quite sound like the person you're talking to. And if it's a person you don't know … I'm, basically, picking up this magical box thing and … and calling a person who lives far away, who I don't know to … to arrange something that I don't really want but need.

He went on to say, however:

> I think with calls, it's always been something that I'm bad at, but since moving away and you know, all of my friends live in different states. So, I … the only way I can communicate with them is via Facebook messenger and stuff like that. So online calls with my friends now is something that I've normalised because I do it enough.

Again, Eric shared how he has taken something that he found very difficult and practised it with people whom he knew until he was able to make it a "normal" part of what he did. Speaking with strangers over the phone, however, appears to remain a key difficulty for Eric (see also Howard & Sedgewick, 2021).

5.9.5. Independence

Personal Development. Personal development is a key area of strength for Eric. Eric's mother described him as being a "high achieving student" throughout school and throughout university. More importantly, both Eric and his mother described his love for learning. Eric stated, "I like study a lot. I've always enjoyed learning things. It's really what gets me up in the morning, I think is, you know, being able to learn stuff." Eric went on to describe how he "absorbs information like a sponge", and how "I can just cruise through [my studies]. I work very hard, but it [study and learning] comes eas[il]y." The different areas of study that Eric has chosen also indicated that he was able to apply his love of learning across a wide variety of topic areas. His initial degree in physics was very different from his current postgraduate studies in the Master of Learning and Teaching program. However, Eric had achieved very highly in both and described what he enjoyed with both. For example, Eric talked about how "I did enjoy my last degree more because there was more stuff to learn when you study science", but that "I really do enjoy teaching. It's really great to see how their minds work. It's so cool seeing how they all think differently and approach it." He had also been able to use his study and work in education to enhance his own understanding of the person that he is: "I see these kids going through the same problems that I went through. There is an immense amount of satisfaction I can get from working with people who are … like, who I used to be, you know, five years ago." This was very similar to Eric's conversations where he talked about how he "learned" how to make friends by taking the skills from one area and using them in another. Thus, it appeared that Eric's high levels of intelligence, and his love for learning across most areas, had indeed been a significant strength throughout his life. High intelligence, while not a guarantee of success, has been shown to provide a positive mediating influence for young people on the spectrum across many domains in life (Halder & Bruyere, 2021; Livingston et al., 2020).

Eric did qualify, however, that these high levels of personal development were not something that he always used. He commented that "I tend to steer away from things initially that I … I conceive as both not being good at, and also not being interested in. I usually challenge myself with stuff that I'm already good at." Eric acknowledged that this was part of the reason why there were areas in his life, such as physical activity and making phone calls, where his love of learning and his ability to learn did not have a positive influence. He did concede that "I reckon, if I applied myself, maybe I could develop to actually be able to do it", so, while Eric did not always choose to learn how to do something, he did share his belief that he could learn it if he wanted to do so.

Self-determination. Eric displayed a very dichotomous view towards self-determination in his life. On the one hand, he indicated that, "Yeah, I'm happy with it. I mean, I feel like my life is very much under my own control and I can take it where I so choose." On the other hand, he stated that, "Ideally, if I could have less decisions and they could be made for me, um, I think it might make life easier." In summary, Eric stated that:

> I tend to leave it up to the winds of fate normally and then make decisions at the very last second. I just sort of watch and see, that's easier, but I don't feel like there's any areas where I have less control than I would like.

Both Eric and his mother talked about "learning" self-determination as something that had been ongoing throughout Eric's life. His mother stated, "I tried to get my children to do things independently from when they were little. Eric just was resistant. He would sometimes do it but hated me [for making him do certain things]." She acknowledged that "I have been trying to get him to do it all these years, and it is still a point of, um, awkwardness or resistance for him." Eric recounted one specific childhood experience where his mother was trying to teach him to purchase something for himself. He emphasised,

> Our entire lives, she tried to push us to do these things and pay for stuff. There's this one moment from my childhood which really sticks out. I so vividly remember just how terrified I was walking up to the counter and paying for these [biscuits]. I can still remember what the store smelled like. That's how ingrained in my memory it is.

Both Eric and his mother appear to have intuitively understood the importance of practising the requisite skills needed for self-determination (Duncan et al., 2022), and the importance of developing self-determination over time (Ryan & Deci, 2017), and both readily admitted that developing self-determination was an ongoing process for Eric.

Despite Eric's acknowledged resistance to making decisions and doing every day simple tasks such as making phone calls or paying for purchases, he did admit that "If I couldn't teach myself how to do things … [it would be much harder]." Eric agreed that he was good at figuring out the things that he needed or wanted to do, and that because of this he had been able to take his life in the direction that he chose. That is, Eric believed that it was his competence in learning that helped to provide him with the autonomy and relatedness needed to achieve self-determination throughout life's domains.

5.10. Bruce

5.10.1. Introduction

Bruce is 38 years old and lives outside a small regional town in southeast Queensland on his parents' property. He was diagnosed with autism and a co-occurring intellectual disability (ID) as a young child, and since that time Bruce and his family have been key members of the autism community within the local area. Both of Bruce's parents, his mother and father, have been heavily involved in the local autism support group since it started 25 years ago, and both were present on the night that I attended the support group meeting. It was through this meeting, and the sharing of my research, that Bruce and his family agreed to participate in the research. Bruce participated willingly in the interview on the night of the support group meeting with no advocate present, and he did not use the AAGST visual cards during the interview. Bruce presented as quietly spoken and shy during the interview unless he was talking about his key interest, aircraft. When speaking about aircraft, Bruce showed a greater willingness to extend the conversation and was more descriptive with his answers. Bruce's mother was interviewed separately after Bruce's initial interview. This interview was conducted at a different location with other support group members present.

5.10.2. Quality of Life Domains

Bruce answered all questions with brief, factual responses, and did not elaborate on topics unless promoted through questioning. To address this, the questions were adjusted throughout the interview to build on Bruce's initial responses and elicit more detail about specific topics. Despite this, Bruce and his mother were very consistent in their responses regarding Bruce's current QoL. In Bruce's words, his QoL would best be described as "tolerable", a word that he used often throughout the interview, with Bruce having experienced both positive and negative periods across most domains. For example, he and his mother described how, for many years, Bruce was employed in his "dream job" where he was very happy. Sadly, the business went into receivership and Bruce had to find another job that he does not enjoy as much. Despite these less than positive aspects of his current QoL, Bruce has been able, with the support of his family, to establish a generally positive QoL that includes many of the things that he values the most.

5.10.3. Wellbeing

Material and Physical Wellbeing. Bruce lives independently in a detached house on his parents' property. Bruce stated that "I live at my parent's place; um, I look after the horses", and "My parents did a thing because they've got that property, and there's two houses on that property." He went on to describe how he spends his days on the property: "Just feed animals, help mum and dad with the mustering. We got a wood contract, and we go down and cut trees and sell firewood." Bruce's mother went into more detail, sharing that "My son lives independently … to a degree", and she outlined the decision-making process that resulted in Bruce's living independently. She described how this was initially Bruce's decision:

> When he said he wanted to go and live independently, we were really excited for him. And so, our response was, 'You know, that's such a great thing to do. If you want to do it, that's fine, we'll support you in that. If it doesn't work, you can always come home'.

The actual move to independent living was a long process for Bruce and his family where "he tried a day, tried a night, tried a weekend, tried a couple of days" until eventually he was comfortable enough to stay in the house on his own (see also

Taylor et al., 2019). Now, after many years of his living independently in the house, Bruce's mother shared that, "He loves being out there. It's solitary and he's happy, he's got his dogs, and he does his own thing out there."

For Bruce, living independently did require support from both his family and outside support agencies. Bruce's mother indicated that "He rings us every night to let us know he's okay", and that they regularly go and visit him at the house, both to make sure that everything is okay and to ensure that he has contact with people. Bruce supported this with the statement, "because I usually ring … just ring about eight o'clock." Bruce and his mother also shared that Bruce received help to manage the household chores through a local disability support provider: "I'm with the NDIS. I got a support worker [who] comes out and she helps me with my housework and stuff." This had been a very positive inclusion in Bruce's life as his mother shared that "He did have this permanent person who would come out and she … she has left. And she's like our age, and they got on like a house on fire." Since the regular support person left, however, Bruce had experienced constant changes in the people who come to support him in the home. Bruce's mother indicated that "He's coped alright with the different … the changing people because sometimes every week there's a different one", but she felt that it was better for Bruce when it was a consistent, familiar person.

Bruce's mother also shared concerns regarding Bruce's living independently. This included worrying "because anything can happen", and that, "if something breaks or something happens, he doesn't always tell us". The family, however, manage this effectively through regular phone calls and because "Bruce's dad is out there half the week", so he is not alone all the time. She also stated that "he has times when he does come home", indicating that sometimes, if he were struggling with something, or if he started to feel lonely, he could always go to his parents' house and stay for as long as he wants, although this had become less frequent as Bruce had gotten older and become more independent.

Employment was another area where Bruce experienced high levels of self-determination, although his satisfaction with his employment had changed throughout the years, depending on the job he had at the time. Bruce stated that his ideal job would be an aircraft engineer. Throughout the interview, Bruce talked about his love of aircraft and his desire to work in the aircraft industry. Bruce and his mother shared that in the past he had had this opportunity, but that his current work was not in this area. Bruce's mother stated, "He was working for a local aviation company and they, uh, went into like a receivership thing, and that was his dream job. He was really well respected out there." When Bruce talked about this job, he indicated that "I was just a cleaner there, but I helped them with the aircraft and … I had a few question marks on how they did a few things with the aircraft." He went on to say that "Then I mentioned it [his ideas on how to do things] and they ended up doing it because they had lots of trouble." When I asked Bruce if he thought that he would ever have the chance to work in the aircraft industry again, he replied, "I could … I could probably do it."

Bruce's current employment was one day a week at the local bacon abattoir. When asked if he enjoyed his work, Bruce replied "Oh, I'm only there for the money, not for the love" (see also Goldfarb et al., 2021). His mother used the exact same words in describing Bruce's view on his current work: "He doesn't particularly enjoy his work. He's only there for the money, not for the love." She went on to share that "When you ask, 'How was work today, Bruce?' His response is 'It was tolerable. I got to see Toby and Taylor'." Bruce's mother elaborated and shared that, after his job with the aircraft company ended, "He didn't want to be out of work." Bruce and his family did an interview for a story in the local paper, and "One of the guys he went to school with read it from out there and went to the HR [human resources] people and said, 'This guy here, give him a job', so he's been there ever since." She proudly stated that,

> He actually got that job as an able-bodied person, not as a supported position. He's had all his other employment through a supportive workplace through a local disability employment agency. He's had quite a few different positions. He's never been fired from any of them, and he's just gone from one to the other.

She also indicated that,

> They really like him there. He does talk to other people; it's probably not really that bad. They've offered him a job to, you know, every day of the

> week if he wants it. But he knows he's on the kill floor and he said, 'I just can't bear there'.

Bruce supported this statement when asked if he would like more work. He replied, "Yeah, no, one day is enough." He felt that he "probably [enjoys] working on the farm a little bit more", and that, on the days that he works at the abattoir, "I leave home at 4:30 at night. I mean, by the time I get home, I usually fall into bed." Thus, for Bruce, one day of work at the abattoir and the rest of the week on the farm were his preference.

In relation to money, Bruce was again primarily independent with some support from his family provided as needed. Bruce talked about saving for a holiday, and that he could do this as well as pay his bills. He did share, however, that "[I've] made a few mistakes with money and things like that." Bruce's mother again elaborated on this statement during her interview by stating that "Bruce had a bill of $2050 that he just paid. He didn't realise he'd been scammed. He just paid it: 'The bill comes, I pay it'." This has happened twice in recent times, and Bruce's mother shared her frustration that, while Bruce was very good at paying his bills, the difficulty was in trying to teach him how to "recognise" when something was not right. This is a very common finding for people on the autism spectrum, with support or oversight often required to ensure that anomalies in finances do not occur (Cheak-Zamora, Teti, Peters, et al., 2017).

Emotional Wellbeing. Bruce described his emotional wellbeing in much the same way as the other domains in his life: "Okay." He acknowledged that, while things are not going exactly the way that he would like, he was content with his current QoL, and it met most of his wants and needs. That is, his material and physical wellbeing were good and, while he could not do exactly what he wanted, such as work with aircraft, he was happy that he had a choice and was able to work one day a week. Bruce's mother also described this choice as being important for his emotional wellbeing: "Because the whole interaction thing is really taxing on him. That's been all he can manage, and he's exhausted." It was a result of the toll that social interactions took on Bruce that she felt, "He loves being out there [on the farm]. It's solitary and he's happy." She also described the importance of routine and structure in relation to Bruce's emotional wellbeing: "Bruce's very much 'These are the rules', you know; it's when something new comes up, now that's another story", indicating that Bruce struggled with changes in routine and structure and could find this difficult to manage. A common finding for autistic individuals is that structure and routine are important for maintaining their wellbeing (Milton & Sims, 2016). Fortunately for Bruce, the routines and structures in his life were stable, and this helped him to maintain a positive sense of wellbeing.

5.10.4. Social Participation

Interpersonal Relations. For many autistic individuals, managing the need for social connectedness, alongside the stress and anxiety resulting from social engagement, can be very difficult. Thus, autistic people tend to be selective with whom they choose to socialise and to ensure that periods of socialisation are followed by periods of time spent by themselves (Crompton et al., 2020). The interviews with Bruce and his mother supported this finding. Bruce talked about his friends: "I have a good friend at work; um, we've been friends since school. He and I talk a lot, talk about work and things like that." However, he also indicated that he liked being at home on the farm where he had time to himself. Bruce's mother was much more specific about this, clearly delineating between the times at work when "he gets to see his mate" and when he gets to "be solitary and do his own thing". She acknowledged that "the whole interaction thing is really taxing on him", but equally shared that, "If we don't, for some reason, when we've been sick and don't go for a week, he's going, 'When are you coming out, when are you coming out?'" Thus, Bruce appeared to recognise the need for a sense of connectedness with his friends and family, while at the same time valuing his own space and time. Bruce also seemed to recognise those people in his life with whom he could connect and be himself. Bruce's mother shared that "He does stuff with us too, by choice." She described the many holidays, trips, and family events in which Bruce willingly and happily participated with his parents, sometimes bringing a friend along. Although Bruce's mother seemed surprised that Bruce would choose to socialise with his parents, it seemed to indicate that it was meeting the need of connection and acceptance for Bruce.

When asked if he would like to have a partner in his life, Bruce replied, "Yeah, eventually." He did not elaborate on this discussion point at all. Bruce's mother, however, shared some insight into this area of personal relations when she commented that, “His high school girlfriend, he just caught up with her after 20 years, and they picked up where they left off … and it went beautifully for a while.” Sadly, there were significant complications owing to her experience of childhood abuse, and so “It lasted about three months and then it ended. It was pretty tragic.” Bruce’s mother confided that “I was pretty upset, and I felt bad because I had asked him if he wanted to make contact again, and he did, so I felt like it was kind of my fault”, and “It’s very sad for him.” This discussion indicated that Bruce’s mother would like Bruce to experience the connection that comes with an intimate personal relationship, and that she was willing to help Bruce to make connections with others that may have led to this.

Social Inclusion. The key supporters of social inclusion for Bruce were his family, work, and the local autism support group. As discussed in the previous section, Bruce engaged in many activities with his family and primarily caught up with friends at work. The local autism support group also organised regular activities for the autistic adults who attend the group. These activities ranged from weekends away, to community barbeques, and sporting activities. Bruce commented that, “Yeah, they’re pretty cool” when he talked about the support group and the activity that they had planned for the following day. He shared that “Tracey, a friend, she does the Aspies [runs the Asperger’s support group] and we’re going out to archery.” He went on to talk about how their group had done archery a few times, and “I’m pretty good at it.” I also noted that Bruce sat and talked with the other autistic adults during the support group meeting, indicating that the group know one another well and were comfortable socialising together.

One area of social inclusion that Bruce did not enjoy was attendance one day a week at disability support at community care. Bruce’s mother laughed when she shared that “On Friday he comes into the centre at community care. He calls it ‘kindergarten’; he hates it!” She did go on to explain that it is a part of the community participation goal for his NDIS plan, and that “He needs to be doing some one-on-one or going as a group to something meaningful for him because, yeah, it’s just that he’s so isolated.” Thus, while Bruce did not enjoy the planned activities at the community centre, it was another important area where he experienced social participation in the community. Disappointingly for Bruce, there were no local aircraft interest groups for him to be a part of.

5.10.5. Independence

Personal Development. Bruce had developed many skills as an adult, with most of them being related to independent living or his interest area of aircraft. Bruce had his driver's licence: "Yeah, I've got my licence. Everyone loves driving with 50 kilometres distance to travel anywhere." Because Bruce lived on a property outside town, getting his licence was a key part of his developing independence. Bruce's mother did share, however, that "It took him a long time to get his licence": "We would take them [the students in the special education program] to help them with their licence." Once he had his learner's permit, Bruce did his driving practice with his parents. His mother stated that "I'd let him drive to school and home again", and "We'd go for trips to do things and he'd drive. So, he had, you know … lots of practice." Having his licence meant that Bruce had been able to live in his own house and to transport himself to work and community activities for many years now. Bruce had also developed the skills needed to manage his own household; cooking, cleaning, washing his clothes, although he did still receive support with this once a week. Bruce's mother indicated that Bruce managed independence by learning skills and using these skills as part of his everyday routines. She stated, "I guess he's kind of used to most things that happen", and that this was how he managed independence in most QoL domains.

A key area of personal development for Bruce was to maintain his interest in, and knowledge of, aircraft. Bruce stated very early in the interview, "I love aircraft. I've loved them since I was five. I'm really big into the war birds thing." He stated, "My favourite aircraft, we've got a few of them here, the T28 Trojan. Yeah [it flies] from the airport here, there's one in Toowoomba, um, there's one in Caboolture." Bruce also shared that:

> I went … it was 2018, I went for a trip up north and visited all the air museums. Yeah. And some of the people I was talking to were really interested in all the stuff I knew … and one of them wanted me to, you know, work for him.

Bruce was not able to take the job because it was too far from where he lived, and there were no local air museums or aircraft interest groups for Bruce to be a part of in his local community. Thus, his love of aircraft is something that Bruce pursued in his own time and had not been able to maintain across all aspects of his life as he would have liked.

Self-determination. When asked if he gets to make decisions for himself, Bruce replied, “Uh, sometimes.” He indicated that when he is not making decisions for himself it was “my parents [who are making the decisions]”, but that they explained to him why certain decisions needed to be made. He did share that there’s “Just one big issue. I like skulls, especially Anne Stokes art.” Bruce stated that his parents did not like the artwork and so he was not able have the artwork that he would have liked in his house. He also shared that “I like heavy metal music”, and again his parents did not, so he could play it only when he was at home in his own house. Although these may seem insignificant, for Bruce they meant enough for him to mention them in the interview.

Bruce also shared that the one thing that he would like to plan for the future was a holiday to the United States, although he did state that it is “Maybe a one-day thing. Very long, long into the future.” Bruce shared that he would love to “Go to LA [Los Angeles], have a look around there. Places in LA, LAX Airport [Los Angeles International Airport]” because, even though he has flown into the airport before, he did not get to look around and see all of the planes and how the airport worked. He also shared that he would like to “Visit Yellowstone and see the Devil’s Tower. It’s a basalt volcano that’s in [the film] *Close Encounters of the Third Kind*.” Thus, Bruce had goals and aspirations for the future that he would like to work towards.

5.11. Piper

5.11.1. Introduction

Piper is 20 years old and lives in a metropolitan city in southeast Queensland. She was diagnosed with autism and attention deficit hyperactivity disorder (ADHD) as a young child, between the ages of three and four years. Throughout her life, Piper received additional diagnoses, including dyslexia, dysgraphia, and anxiety. Despite the numerous diagnoses, Piper had followed a very typical path for a young adult. At the time of the interview, she lived independently with her boyfriend and was studying a double degree in psychology and counselling at a metropolitan university. Piper also worked part-time as a disability support carer under the NDIS. For Piper, however, she had found that the longer that she lived as an independent adult, the greater the difficulties that she encountered.

Piper and her mother were interviewed together and responded to questions either sharing the same opinion, or specifically sharing differences in ideas. Throughout the interview, the extremely close relationship that they shared was evident, with both including many stories and jokes as they responded to the interview questions. Piper did not use the AAGST visuals and spoke openly and confidently about her perception of both her QoL and her experiences at school.

5.11.2. Quality of Life Domains

Throughout the interview, Piper shared many perceptions about her QoL across all domains. Overall, as with most young people in the early stages of transitioning to post-school, Piper had had both positive and negative experiences and had gone through a great deal of learning and adjusting to become an adult. She did share that the initial transition was a very confusing time: “It was like ‘Where do I go from here?’ That was what it was like for me.” “It was like, a wave [from the school] and then a shut to the door to your face.” Both Piper and her mother stated, “We had to do it ourselves [transition to post-school].”

Piper’s mother also described the additional concerns that she and Piper’s father had experienced during this transition period. She shared that, “It can be really challenging. I can’t do it for her”, and “I observe her struggling with how to adult with certain things. Which is really hard because you watch them fail and you know they’re going to fail.” Furthermore, she felt that:

> I still worry probably more for her because it’s hard to know whether the interventions and the processes that we put in when she was diagnosed at three or four are solid enough to give her that base of … of good decision-making.

As a parent, Piper's mother articulated that "We used to have everything planned so well", but now "You don't know what decisions they're going to make. So, you always feel like you're on the back foot." Acknowledging that "It [autism] is lifelong … they're not going to grow out of this", you watch them "struggling with how to process certain challenges and how to work through certain stresses."

5.11.3. Wellbeing

Material Wellbeing. Living arrangements were one positive QoL domain for Piper. Her mother initiated the discussion around material wellbeing by stating, "She's got a roof over her head, she's got a car, a partner, food, job, all those key components of stability." Her unit is "The way she wants it with the things that she wants and needs around her"; it's "One that she chose, they've decorated it beautifully." For Piper, "living independently" was key to what she wanted as she moved into adulthood, and she was very grateful to have her "own place". She did, however, also recognise the importance of still having her family's support in managing this independence.

Two areas of material wellbeing that have been more difficult for Piper were gaining employment and managing her finances. Piper shared how, "I was struggling with work because I'd just finished school and everywhere wants you to have five years or more experience, and I'm like, 'Well, how am I supposed to get that?'" Eventually, Piper was able to use her strengths and gained employment as a support worker with the NDIS: "I really did like helping people and helping people like myself. I've always been like that, but ever since I started becoming a support worker … I really love NDIS." Furthermore, "You're getting that experience": Piper feels that her work is providing valuable experience towards her future career. While Piper described how she enjoyed her role as an NDIS support worker, she also shared that, "A lot of time I struggle at work because I don't remember to do things or I … it looks like I'm being lazy, but I get flustered", and "people think that I'm not working as hard as I am" (see also Anderson et al., 2021).

Money was the other area of material wellbeing where Piper admitted that she had a lot of learning to do, and that she had struggled consistently since finishing school. She stated,

> Because it’s like, in order to live, you need money. And I wanted to do all the things like have my car and drive around, go out with my friends and stuff, but I didn’t have the money for it.

She described how when first leaving school it was difficult “working for $15 an hour” and trying to live independently. Although Piper lives in the unit with her boyfriend, she shared that “I’m the main earner. Because he works in the airline industry, and because of Covid, he’s not earning money.” For Piper, she felt that “It’s not a problem that you can just fix like that [clicks fingers]”, so “It was mainly like finances, which made … I think that was like the tip [of her increased anxiety levels].”

The transition to university was described by Piper and her mother as another QoL area where both Piper and her mother experienced high levels of stress. Piper’s mother described how Piper was accepted for early enrolment in the degree that she chose; however, while “It took the pressure off, it still didn’t really then help with the accessibility.” She shared how they thought that “We would sign a form saying we give the university access to all this information and that … that gets passed on from the school.” Yet their experience was the opposite of this: “There was no communication. So, there was no documentation sent to the university, there was no meeting set up. We kind of thought, wrongly … I assumed we would see this smooth transition, but it wasn’t.” Both stated that it “Felt like starting again. It didn’t seem to matter that we knew … like that we had done this for years; it felt like we didn’t know anything.” Furthermore, even after realising that they had to set up support, Piper felt that “It was really unclear about what they actually needed from me.” In the end, Piper’s mother described how “The university wanted updated stuff [a formal diagnosis], and I said, ‘Well, we’re not going and paying a lot of money for a new one’.” Piper shared her main frustration as, “There was time for me to have that extra help considering I had already gotten in. They could have all the rest of that term to support me.” The perceived lack of support for the transition from school to university is not unique to Piper’s experience. Research has consistently shown that transitioning to university is an area of difficulty for young people on the autism spectrum (Cai & Richdale, 2016; Ward & Webster, 2018). Specifically, the years of knowledge about appropriate, individualised support from school are not continued into the university setting, and for many the process was like starting again (Thompson et al., 2019).

Physical Wellbeing. When asked about her physical wellbeing, Piper focused on the sensory sensitivities that she had experienced since leaving school: “I have become very aware [of my sensory sensitivities]. I have lots of sensory issues, actually. I think because you notice … you can take the time to notice.” She went on to describe how, “Because of sensory issues with healthier foods, I find it harder to eat healthier things”, and “like I can’t eat peaches because of the fur; even that makes me [sticks tongue out and shivers].” She did share that “Now I’ve moved out I’m able to buy those things” that she likes to eat, although she feels that this does not contribute positively to her physical wellbeing because she is not eating as healthily as she should (see also Singh & Seo, 2021).

Emotional Wellbeing. Piper’s mother stated, “I think her emotional wellbeing fluctuates a lot and it depends on so many factors.” Piper supported this statement by describing how, “Ever since I left school, I’ve noticed that [emotional wellbeing] more.” She went on to state that, “I honestly didn’t feel like I had it [anxiety] at school, but now I have definitely got anxiety because … I don’t know why. I got diagnosed with anxiety when I finished school.” Piper’s mother, however, explained that she believed Piper had always experienced higher levels of anxiety but, because of the structure and support provided throughout her schooling, she was able to manage it: “She already had it, but it was … it then changed.” Piper agreed that her anxiety levels had changed, stating “I think I did get it because of everything; the stress of everything was just too much.” Increased anxiety is a common experience for young autistic adults as they navigate the increased expectations and responsibilities associated with adulthood (Hull et al., 2017).

The emotional support provided to Piper by her family was emphasised by both Piper and her mother. Piper’s mother shared that she always had, “A home to come back to, parents, two parents, which is unusual, brothers. She still knows that she is loved, and the door is always open. She can still come and get the emotional support and talk about things.” Piper shared a recent example when her boyfriend talked to her about the possibility of joining the Australian Airforce so that he could be employed as a pilot. Piper explained, “I basically had a breakdown and like a manic episode because of the thought of him leaving." She went on to share that, "I drove straight to mum and dad's place" and "she [Piper's mother] goes, 'Whoa, calm down', because I start to like [breathes rapidly], you know." Piper reiterated, "That happens like when things are stressful or there's something I need to talk about." The emotional support provided to Piper by her family in these types of situations allows her to navigate the stressful and difficult times that she faces in living as an adult and is a common experience for the young adults in this study and in the wider research (Mattys et al., 2018).

Finding outside support services for her emotional wellbeing as an adult, however, had not been easy. Piper's mother explained that "There was no referral to adult services. The paediatrician didn't refer us to a psychiatrist, so we didn't have any referring psychiatrist." Piper added to this discussion, sharing how her paediatrician said that she would no longer be seeing Piper as a patient, "She basically said, 'You need to find someone else now because you're eighteen'. And I was so confused. How did they expect me to know what I was doing? I don't know what I was doing. Mum told me what to do my whole life with this stuff." When describing this last meeting with the paediatrician, Piper's mother exclaimed, "She actually dismissed me. She said, 'I'll see Piper on her own for her last one, because she'll be 18.' I was so shocked!" Following this last appointment, they found it very difficult to find appropriate adult services: "We rang about five different psychiatrists, looking for someone who would take Piper on as a patient." Piper's mother shared that "We finally found someone through word of mouth, but it took a while to find her because nobody wants to take on an adult with ASD and ADHD." Piper described how she felt very "let down" by the process: "The part that I think I was most annoyed about was that I didn't have any help on that stuff. It was up to us to do it all." This experience of a significant divide between child and school-based health-care services and adult health-care services was referred to often in previous research (Cheak-Zamora, Teti, Maurer-Batjer, et al., 2017).

5.11.4. Social Participation

Interpersonal Relations. Piper reinforced the changes that she had experienced in her interpersonal relationships since leaving school and described this as one of the positive QoL areas as an adult: "It's hard in other ways, but socially you get to pick and choose who you want to be with." She went on to explain that "I'm very picky about who I let into my life now. Like you don't care about that stuff [popularity] now, so then you care more about actual genuine friends." Piper's mother supported this with the statement, "The world is not quite as harsh as high school socially." Piper talked enthusiastically about the important friendships that she did have: "I've got my best friend Evie; I've known her since I was four" and "I've got my horse-riding best friends." She explained that Evie is the daughter of a friend of her mother's, and that she has made new friends through her since they finished school, "Now we're all friends. And her best friend is now one of my best friends." Piper did share that, "I don't really have any friends at university because I do find that hard, making friends at university. It's kind of like starting school again", although "I have a few friends at work … well, I got like two. But they're in their forties!"

A key personal relationship for Piper is her boyfriend, Jason. Piper described Jason as "My emotional support … like a rock." Jason and Piper started dating towards the end of secondary school and moved in together after finishing school. Throughout the interview, Piper often mentioned the role that Jason played in her life, from supporting her at school and university, to helping her to make key decisions, to acting as a social support (see also Mattys et al., 2018). Piper talked openly about her and Jason's long-term plans to get engaged, get married and have children. While Piper's mother shared that her and Piper's father would like them to wait and "see the world" a bit before settling down, Piper was adamant that, "I don't want to wait too long. I don't want to travel first. I did that enough when I was young."

Social Inclusion. Piper's social inclusion is very similar to that of a nonautistic young adult. That is, she is engaged in the community through attending university, going to work and engaging in horse-riding, an activity that she has done throughout her childhood and in which she continues to participate. Each of these activities occurred unsupported and as a natural part of her everyday life. Thus, Piper perceives her social participation very highly. She described her choice regarding what social activities in which she was involved, and with whom she did these activities. For young autistic adults, achieving social inclusion through natural, everyday activities is an important and valuable achievement (Cameron et al., 2021).

Human and Legal Rights. Human and legal rights for Piper related strongly to her diagnosis of autism and ADHD, and to how this diagnosis impacted on the way that people perceived her. She acknowledged that, “Once you have a diagnosis, you always have the diagnosis”, but “I think I’ve become more like one with it, more accepting of it.” Importantly, Piper stated that, “I’ve realised in that little world of school, it mattered, but in the big world it doesn’t”, and “It doesn’t impact on me in negative ways all the time.” This shift in attitude has occurred since transitioning out of school, as Piper indicated that “In school I always tried to hide it.” Moreover, it shows a significant change in Piper’s acceptance of herself and her acceptance of her autistic identity (see also Cribb et al., 2019). This self-acceptance was a positive change and had led to Piper seeing herself in more of an advocacy role: “Even with new people I meet, I’m very upfront about it because I wanted to normalise it.”

Piper went on to share that she believed that there is now a much greater level of understanding and acceptance of autism and ADHD within the community:

> The movement [towards acceptance], yeah, I’m seeing it myself personally. I’m seeing it within the community. Especially on social media, there’s lots of influencers that are coming out, saying, ‘I’ve got ASD or ADHD’, and it’s becoming really more normalised.

She reinforced that, “I love it because it makes me feel a lot more normal, you know. It’s also teaching everyone else that it’s normal.” She finished by saying, “There’s always room for improvement, but I feel like it’s pretty good.” Piper’s mother agreed with Piper’s view on this, stating, “There’s more acceptance around the diversity because it brings richness, and I like that”; however, she did still feel that “They’ve got to be able to cope with the world not understanding them [all the time].”

5.11.5. Independence

Personal Development. It can be seen throughout the interview that Piper has continued to develop and learn across all QoL domains. In many of the domains, new experiences and family support allowed her to continue developing her skills as an adult – for example, navigating finding medical support and managing interpersonal relationships. Piper admitted that the skills and knowledge that she values are things that she would work hard towards, whereas when she was struggling it could be harder to stay motivated. An example of high value was when Piper talked about getting her driver's licence and how "I really wanted it. The day that I turned 16, [I] went to the Department of Transport to go for my learner's licence, then I was persistent about driving all the time." An example of struggling to stay motivated was her discussion of university studies.

Piper shared, "I'm really struggling at the moment. I'm struggling because I hate study. It's not enjoyable. I really don't like it." While she acknowledged that she found her university lecturers very supportive, "I've never had anyone reject it [an assignment extension]. I've had one lecturer, when I asked if I could have a week off, she offered me more [time]", and "I have my exams in a different room and get more time", Piper described how "I hate studies. I'm not good at it." Piper went on to explain that:

> It takes a lot of effort; it's not as simple as just sitting down and writing something up. I find it really hard because I've also got dyslexia and learning dysgraphia, and so it's really hard for me. I actually have to plan my days so I have a full day for uni. I can't go out and then come and do a little bit of study.

She admitted that "The only reason I'm doing it is because I want to get … finish it so I can get paid higher, basically."

Self-determination. When discussing her level of choice and control in her life, Piper stated, "I'm very adamant [about] it because I've always been very independent." She went on to share that "I think I try to cope with it [life] as much as I can. Then, if it gets to the point where it's just too hard or … it's like too much for me … then I get mum to help because by then I'm stressing." She went on to say, "I try and problem-solve as much as I can, but sometimes you want to talk about things to other people." Piper's mother commented that "They need to experience it and work it out themselves and are quite happy to tell you that they want to work it out themselves. Because they're, by that stage, emerging adults and they want their own decisions." She admitted that, as an adult, "She [Piper] doesn't have to listen to us at all. We've always tried to put in these strategies and these skills, but at some point, we also know that we've got to let go of the reins and let them work it out." Furthermore, Piper's mother explained that "One of the realisations is that I probably did too much for her. We thought we were building habit, but actually it was just doing it for her to some degree", and "It's hard as a parent to go … They've actually got to work it out."

Piper shared a key example of self-determination when she talked about buying her car: "I don't feel like I've got the right car. And I didn't get the best price, and I didn't … you know, I didn't know I could even talk them down." She elaborated that, "I went on my own because I was trying to be an independent adult, and I thought I was doing the right thing", but "because I didn't ask my dad for help, I didn't think it through properly." She is now paying off a car that she's not completely happy with. Piper did admit that "Now I'm ready to go, 'Ok, I need support on how I manage this'", and she talked about working with her father to sort out her car finances. This is an example of how self-determination and autonomy do not ensure that the right decision will be made every time, but they do provide valuable life lessons (Seale & Chadwick, 2017). For Piper, the high level of self-determination that she has was evident in her readiness to admit that she should have asked for help, and in her willingness to go back and ask for help now.

The future was perceived very positively by Piper, and she happily shared her goals: "I want to get engaged soon. I've very much wanting to settle down." Piper explained that "I do want to have kids. I want to have kids young, like, in the next three years." Although she did mention that "I'm aware they might be like me, you know, have ASD or ADHD, I'm not concerned. I'm just, like, aware of it, and I'm hoping by then there's more help." Regarding her university study, Piper was less sure if she wanted to continue with this, given that she was finding it so difficult. Piper's mother felt that "she might make a decision about other things like deferring university or reducing her workload to make it easier", but she was hopeful that she would eventually graduate. In terms of work, Piper stated, "I want to stay in [the] NDIS. I'm not too sure about if I want to be a case manager or what, but I love working in [the] NDIS." Thus, she wanted to continue in her career of helping people like herself.

5.12. Chapter Summary

Throughout Chapter 5, the stories of the nine young adults have been shared. Each young adult's perception of his or her QoL was shared through examples provided within the eight QoL domains. The QoL of the young autistic adults was positive. Although all the young adults had experienced difficulties within their QoL domains, none of them had expected everything to work out exactly the way that they had planned, and all showed significant levels of resilience in continuing in the development of their self-determination and a positive QoL.

All the young adults experienced positive levels of material, physical and emotional wellbeing. Most of the young adults shared that they had chosen to live where they were living, whether this was with their family or in their own home. Frank was the only young adult who was currently living with his family and expressed a desire to live in his own home while simultaneously sharing that he did not know how he was going to make this happen. All the young adults were financially secure enough to live comfortably, and many shared plans for their future. These plans included greater independent living, such as moving overseas or getting married and saving for holidays. All the young adults were content with their current employment, even if they were working towards changing this through studying at university. Although all the participants described the high levels of stress and anxiety that they experienced across various QoL domains, they also all described the strategies and supports that they used to manage this stress and anxiety. Overall, the strategies and supports provided allowed the young adults to experience a primarily positive emotional wellbeing. Again, Frank was the one young adult whose experiences were more negative than positive in this QoL domain.

Social participation was a QoL domain that showed potentially significantly different subjective perceptions from what would be expected based on objective measures. That is, while all the young adults shared that they have a small number of interpersonal relationships and social experiences, most spoke openly about the importance of quality versus quantity of social interactions. They viewed the small number of close relationships that they experienced as more important than having many friendships and spending large amounts of time in social situations. Family relationships and family support were considered crucial to a positive QoL for all the participants; however, only a small number of the young adults interviewed expressed an interest in finding an intimate partner. Piper shared the important role that her partner played in her life, while Tamara spoke of the positive relationship that she had had with her boyfriend throughout school. Both Frank and Eric expressed a desire to find an intimate partner but shared the difficulties that they had had in doing so. All the other participants indicated that it wasn’t an important part of their lives at this time.

Importantly, all the young adults interviewed shared that they experienced high levels of personal development, particularly in the areas that they valued, and that they perceive themselves as having high levels of self-determination. That is, the young adults felt that they were able to make the choices needed to achieve what they wanted. Furthermore, the young adults believed that they would receive the support that they needed, and they saw this support as contributing to their self-determination rather than reducing it. Frank was the one young adult who expressed high levels of conflict between the level of independence that he wanted and the level of autonomy that he had achieved to date.

CHAPTER 6: QUALITY OF LIFE CROSS-CASE ANALYSIS

6.1. Chapter Overview

In this chapter, the cross-case analysis of young autistic adults' quality of life (QoL) is addressed in response to Research Question 1: ***How do young autistic adults perceive their current quality of life?*** The preceding chapter provided a rich description of each young adult's perceptions of her or his current QoL across the eight domains of the QoL located within the three overarching QoL factors of wellbeing, social participation, and independence (Schalock & Verdugo, 2002), and was used to identify the commonalities and differences across cases within each of the domains while ensuring that the uniqueness of each case was retained (Stake, 2005). The eight QoL domains addressed in this chapter consist of material wellbeing, physical wellbeing, emotional wellbeing, interpersonal relations, social inclusion, human and legal rights, personal development, and self-determination.

As discussed in Section 5.1, both deductive and inductive coding methods were used throughout the analysis (Miles et al., 2014). Deductive coding related to the use of the eight predetermined QoL domains listed above. Inductive codes emerged progressively throughout the analysis as I became aware of important factors that were highlighted within the QoL domains for each participant and of emerging factors that did not easily fit within the eight QoL domains. These inductive codes led to the development and recognition of the key findings identified relating to the young adults perceived QoL. The key findings of ***family support***, ***outside support***, ***strengths and interests,*** and ***resilience*** summarise the key factors that influence a positive QoL for these young autistic adults. ***Family and outside support***, while mentioned in the domain descriptions, emerged as a key indicator that facilitated a positive QoL across all other domains. ***Strengths and interests***, also mentioned in terms of things in which the individual was interested, emerged as critically important to facilitating a positive QoL across all domains for autistic individuals. The code of ***resilience*** was not mentioned with the QoL domains specifically; however, it emerged as a key indicator of a positive QoL across all domains. Furthermore, ***resilience*** is not typically associated with autistic individuals and how they navigate QoL challenges, yet it proved to be a significant finding of this study.

The cross-case analysis was guided by the conceptual framework presented in Chapter 3, thus considering the cross-case analysis of QoL from a strengths-based approach under the umbrella of self-determination theory (SDT) and a biopsychosocial model of disability for young adults on the autism spectrum. Under this umbrella, both the personal characteristics and the environmental supports and adjustments provided for the young adults were considered for both similarities and differences across cases. Throughout the discussion, examples from individual participants and their parents were used to provide a justification for the key findings across the QoL domains of wellbeing, social participation, and independence. Broad explanations were proposed, and inferences drawn across cases to inform and understand more comprehensively the QoL experienced by young autistic adults who have transitioned from secondary schools (Merriam & Tisdell, 2016).

The key findings across the nine cases, in relation to the participant's perceptions of QoL, included the following:

- Across cases, most young autistic adults perceived their QoL as positive, although all had experienced some difficulties across a range of domains.
- Family and outside support was critical for supporting a positive QoL as the young adults transitioned from school to post-school options.
- The recognition of, and the inclusion of, the strengths and interests of the individual contributed significantly to overall QoL across the domains.
- Autistic adults showed high levels of resilience as they navigated the transition to post-school options. When faced with poorer QoL within a domain, they showed a willingness and an ability to make different decisions, albeit with support, to achieve more positive QoL.

The remainder of the chapter will discuss the cross-case analysis of the young autistic adults' perceptions of their QoL within the 8 domains of the QoL framework. This cross-case analysis will show how the above four key findings were determined.

6.2. Subjective Quality of Life

Understanding QoL in autistic adults can be conceptualised through the QoL domains and how these are influenced by SDT and the values of autonomy, competence, and relatedness. As discussed previously, QoL can be assessed according to either objective or subjective measures (Deci & Ryan, 2002). For this research, subjective QoL was analysed across cases, with consideration of the commonalities and differences associated with how the young adults felt about their QoL across the eight QoL domains. This was an important differentiation within this research. Subjective QoL does not directly compare QoL with that of other individuals. While objective QoL has an implicit understanding of what is positive and negative in terms of QoL, subjective QoL does make implicit assumptions but searches for the perception of the lived experience of the individual (Deci & Ryan, 2002; Erez & Gal, 2020).

According to objective QoL assessments, living independently is implicitly understood as positive, while living at home is implicitly understood as negative. However, this assessment is applied regardless of how young adults perceive their current living arrangements. Consider the examples of Piper and Eric, who were both attending university. Piper described living independently in her own home while attending university, but she emphasised the high levels of stress that she experienced as she managed the routine expectations of both study and everyday chores. She also described the high levels of social isolation and loneliness that she experienced while living independently. Eric had chosen to live at home while he continued university study, and he described the benefit and flexibility provided by reduced daily living chores so that he could focus on his studies. He also emphasised the value of the social interactions and emotional support provided to him by his family while studying at university. From this example, the importance of considering subjective QoL was evident. Under SDT and the biopsychosocial model of disability, typical objective measures of QoL cannot automatically be considered as positive for young adults on the autism spectrum. Subjective perceptions of QoL take into consideration whether the young people would choose this condition if they had other options. This allows a greater consideration of the interplay between QoL domains and the influence of both personal and environmental factors when determining QoL (Claes et al., 2012).

6.3. Material Wellbeing

Within the QoL domains, material wellbeing considers the appropriateness of the housing or living conditions of individuals, their financial status and their employment (Schalock & Verdugo, 2002). Each of these aspects of material wellbeing is closely connected, given that employment typically leads to improved financial status, which in turn can provide safe and comfortable housing and living conditions. For the participants in this study, consideration of material wellbeing was taken from the perspective of SDT. That is, did the individual participants believe that they experienced autonomy, competence, and relatedness within their employment, financial status, housing, and living conditions?

6.3.1. Employment

Employment is a key indicator of QoL outcomes for all adults, including autistic adults. Employment has been shown to provide not only improved financial security but also a sense of purpose for the individual and improved community connectedness (Anderson et al., 2021; Mai, 2019). For the participants in this study, employment was a key point of discussion in the interviews. Six of the nine participants were currently employed either full-time, part-time, or on a casual basis. One participant was volunteering and hoping that this would lead to employment, one was currently unemployed and looking for work, and the final participant was unemployed but not looking for work. See Table 6.1 for the employment status of the participants.

Table 6.1

The Employment Status of the Participants

Participant	Employment status
Anne	Casual employment – cleaning
Bruce	Part-time employment – local abattoir
Eric	Casual employment – teacher aide

Frank	Volunteering – hoping for employment in an Aged Care facility
Helen	Unemployed – not looking for work
John	Full-time employment – kitchenhand
Paul	Casual employment – making beehives
Piper	Casual employment – NDIS support worker
Tamara	Unemployed – looking for work in childcare

Importantly, most of the participants perceived their current level of employment as being satisfactory or perceived themselves as being comfortable with that level. John, Paul, and Bruce all expressed satisfaction with their work, and both Bruce and Paul stated that they were content with being part-time and casually employed with no desire to seek full-time employment. In fact, Bruce’s mother stated that he could be employed full-time but that he chose not to be as he felt it would negatively impact on his wellbeing. Anne, Eric, and Piper were all working on a casual basis while studying at university, and Helen saw this period of recovery from a negative employment experience as important for her mental health. Frank and Tamara were the two participants who were not currently happy with their employment status, and both were working hard to change this, with Frank volunteering and completing studies to improve his employment opportunities, and with Tamara, having completed her traineeship, actively applying for positions. Additionally, all the participants shared that they were happy with their employment area, as most had followed their strengths and interests or were using their employment to be able to follow their strengths and interests. For example, Paul worked on a casual basis making beehives, and spent the rest of his time running the local social media weather group, and Anne was working as a cleaner while waiting to start studying history at university. Bruce was the only participant who was not currently engaging in a strength and interest in his workplace or working towards employment in his strength and interest area.

All the participants utilised both family and natural supports to gain and maintain employment opportunities. This supported the findings of Anderson et al. (2021), who suggested that employment for young autistic adults was most successful when appropriate supports were provided. Furthermore, these supports can be provided by family, support agencies, or naturally within the workplace. A combination of all support strategies was being utilised effectively to maintain the employment of the individual research participants. John, for example, had gained employment through a personal connection made via work experience that was established by his mother. He had also gained additional experience in hospitality by working in his stepfather's café. After employment had been gained, natural supports were established within the workplace to ensure that John was supported as needed. Additionally, John's mother had developed and maintained a relationship with John's employer to assist with any specific issues that needed to be addressed. Similar stories were evident with all the participants, with variation only in the specific type of support provided. Thus, the participants in this research study had ***varied employment with high levels of natural, structured, and family support.***

Appropriate supports most often established through or provided by the family had been critical to the employment success of the young autistic adults, similar to findings shared by Anderson et al. (2021) and Ghanouni et al. (2021). Furthermore, these high levels of employment, combined with family support, had resulted in positive overall financial circumstances for each participant. For the participants in this research, critical links among autonomy, competence, and relatedness had been established for employment. That is, being able to choose employment from employment options, feelings of competence within the job, and high levels of support provided to the young adults for their participation in the job all contributed to positive QoL in employment. Participant Helen, who had had a negative employment experience, described how she had not followed her interests, had not felt competent in meeting the employer's expectations, and was not provided with appropriate support and adjustments in her role. In turn, each of these factors had contributed to a negative sense of QoL and wellbeing for Helen.

6.3.2. Financial

When considering financial status, it is critical to consider not only how much money that individuals have, but also how those individuals are able to use their money to support their overall wellbeing (Cheak-Zamora, Teti, Peters, et al., 2017). All the participants expressed a comfortable level of financial wellbeing; that is, they considered themselves to have enough money to look after themselves and to enjoy the things that they wanted. The financial incomes of participants came from either employment or Disability Support Pensions (Australian Government, n.d.) or a combination of both. Thus, financial provision came from natural support within the community, employment and/or government support, as they would for any other Australian community member. The prominent role of the family in financial wellbeing, however, was in supporting the young adults to manage their money and to ensure that it was used to support their wellbeing, social participation, and independence. Previous research conducted by Cheak-Zamora et al. (2017) and Ghanouni et al. (2021) also found that high levels of financial support were provided to autistic adults by their family to ensure their wellbeing. Furthermore, these studies found that families also continued to provide oversight of the young adults' financial affairs in response to their perceived financial vulnerability, with this finding replicated in the current research. Across the literature, financial vulnerability has been found to be a major obstacle to financial independence and to maintaining the autistic adults' wellbeing (Duncan et al., 2022).

Eight of the participants shared that they had initial difficulties in managing money and budgeting after leaving school, and all the participants and their parents indicated that they required ongoing ***high levels of family support to manage money and to budget***. Additionally, while families assisted the young adults to manage their own money by teaching them how to budget and by overseeing their budget, families also provided additional support such as encouraging the young people to live in the family home, providing them with food and basic everyday necessities, and taking on many roles to prevent the young people from having to pay for outside support. Examples of these roles included providing driving lessons, taking the young person on family holidays, and organising natural community activities such as sports and club membership. This level of family support could be considered very typical for most young adults transitioning from school to post-school as they navigate the changes in transitioning from adolescence to adulthood. The difference with the family support provided for autistic adults was that the support was required for a much longer period of time (Cheak-Zamora, Teti, Peters, et al., 2017; Mattys et al., 2018). Although Frank, Bruce, and Paul were all aged in their 30s, Frank and Bruce's mothers spoke about their roles in overseeing their sons' finances to ensure that they were not left vulnerable to being taken advantage of or scammed. Thus, while many typical adults have learned budgeting skills and are financially independent by this time, autistic adults may continue to require financial support. These findings supported Mattys et al. (2018) suggestion that the transition from adolescence to adulthood may take longer for people on the autism spectrum, and that, for some, specific support may be required throughout the lifespan.

6.3.3. Living

Of the nine young autistic adults in the research study, six lived in the family home with their family and three lived independently of their family. Those still living at home had chosen either to stay at home after school or to have returned home after spending time living away. The primary reason for still living at home for the participants was that it provided additional levels of support while key transition milestones were being reached (Ghanouni et al., 2021). For example, Anne and Eric chose to live at home while they completed university studies, while Tamara also stayed at home while finishing her traineeship and looking for work. Helen chose to stay at home and save money so that she could fulfil her goal to travel overseas, and Paul lived at home so that he and his father could share expenses. All the participants expressed an interest in moving out of the family home and living independently, although all viewed the option to live at home as their own decision and one that could support their wellbeing (Mattys et al., 2018; Ryan & Deci, 2017; Taylor et al., 2019). Thus, ***remaining in the family home was viewed as an autonomous decision***.

Frank was the only participant living at home who expressed frustration with not being able to live independently, although he did acknowledge that he had “things to learn” before he could successfully manage independent living. For Frank, there appeared to be considerable gaps between his need to live independently, and thus experience autonomy, and his competence in the skills required to do so safely, thus meeting his need for wellbeing. For Frank, his limited daily living skills impacted negatively on his ability to make the choice to live independently, as has been found to be the case for many young people on the autism spectrum (Duncan et al., 2022). Additionally, this uneven experience across the three self-determination needs, autonomy, relatedness, and competence, had resulted in Frank experiencing frustration and reduced wellbeing with regard to his living arrangements (Ryan & Deci, 2017).

The three participants who lived independently, John, Bruce, and Piper, all shared that ***high levels of family support were required to maintain a positive standard of living***. All three young adults and their parents described how the young adult had made the choice to live independently, indicating high levels of autonomy. Additionally, all described how their families supported their decision and provided support for the move to independent living, indicating high levels of relatedness. For Bruce and John, ongoing assistance was provided through the established provision of NDIS, financial and emotional support, while for Piper the key supports required were financial and emotional. As with financial supports provided by the family, supports for independent living are typical for young adults transitioning to post-school adult living options (Arnett, 2014). For young autistic adults this support may need to be more intense and more structured, and to continue for as long as is needed, often well into adulthood (Taylor et al., 2019).

6.3.4. Physical Wellbeing

All the participants presented as having high rates of physical wellbeing and expressed a high level of satisfaction with their physical wellbeing. That is, no participants or their families indicated that they had experienced any specific illnesses or difficulties with physical wellbeing. Those difficulties that were discussed by the participants related to common autistic characteristics such as sensory sensitivities, as described by Piper, and physical tics, such as the shoulder and verbal tics described by Tamara and her mother. All other comments related to physical wellbeing were closely correlated with emotional wellbeing. For example, John and his mother discussed his high heartrate and the link that this had with his anxiety level, and Paul described his need to take supplements to address his high levels of anxiety. This finding could be considered unusual for autistic participants, as research cited by Howlin (2021) indicated that individuals on the autism spectrum experience higher rates of physical conditions such as seizures, immune conditions, gastrointestinal and sleep disorders, cardiovascular disease, and other medical conditions than nonautistic individuals. The small number of participants, and the young age of the participants may have contributed to the differences in these findings.

6.3.5. Emotional Wellbeing

Throughout the interviews, all the participants and their parents described ***high perceived levels of stress and anxiety*** experienced by the young autistic adults. Although the environments and situations that caused these high anxiety levels, and the ways in which these high levels of anxiety were expressed, were highly variable, high anxiety was a crucial aspect of the perceived emotional wellbeing of all the participants (Spain et al., 2018). The descriptions of the participants' QoL referenced both high anxiety and the strategies that they developed, or the supports required, to overcome the anxiety. John's mother described his "ever present anxieties" and the resultant "high heart rate" that he experienced, while John described the strategies that he used as "taking deep breaths and ringing the taxi company". Frank and his parents spoke about his high levels of anxiety and his use of physical strategies such as walking, running, and jumping to reduce this anxiety. Piper spoke about experiencing "meltdowns and panic attacks", Eric described the social anxiety experienced when he had to use the phone to make phone calls, and Helen stated that she stayed "just in the house" in response to her anxiety. Smith et al. (2019) suggested that anxiety is a significant area of challenge for people on the autism spectrum, and the participants in this study supported this finding.

Moreover, Bishop-Fitzpatrick et al. (2018) and Smith et al. (2019) also found that individuals' resilience to stress can significantly influence their perceptions of their overall wellbeing. This finding was important to the present research study as it was evident during the interviews that the young autistic adults in this study experienced ***high levels of family support to manage their perceived anxiety/stress***. Family support was critical to managing the young autistic adults' anxiety and perceived stress, and to helping them to develop and utilise appropriate strategies. All nine participants spoke about the significant emotional support provided to them by family, and about the important role that this played in keeping anxiety and stress levels at a manageable level. Anne and Helen both spoke about the importance of being able to talk to their mother to address perceived stress; similarly, Eric and his mother described how being able to "talk about things" supported Eric in processing everyday life and in making the decisions that he needed to make. As shown previously (Schalock, 2010, as cited in Smith et al., 2019), when stress or anxiety levels increase beyond the limits of the individual and when there is no mechanism, such as family support, to balance this, perceived emotional wellbeing may decrease. Thus, while the young autistic adults in this research study experienced high levels of stress and anxiety, the emotional support provided by family prevented this stress or anxiety from reaching critical levels and helped the young people to recover from the impacts of high anxiety as needed. Importantly, this was evident for all the young adults, regardless of where they lived. John, Piper and Bruce all spoke about the emotional support provided by family, even though they did not live at home, while Eric and his mother described the critical role that daily phone calls had had when Eric was living in another state.

Tamara was the one exception to this finding. Both Tamara and her mother described the difficulties that they had in understanding the other's point of view, with Tamara feeling that she was "misunderstood" by her family, and Tamara's mother feeling that Tamara could be "quite mean". Although Tamara did not describe the same perceived high levels of family support as the other participants, she did describe the high perceived levels of support provided by her "teacher aide from school", her "friends", and her "church group". Thus, Tamara experienced high levels of support even though it did not, from her perception, come from her family. In turn, this high level of support encouraged a positive sense of emotional wellbeing from Tamara.

Another key component of emotional wellbeing was described by Huggins et al. (2021) as levels of emotional self-awareness that are an important predictor of social and emotional outcomes. Although Huggins (2021) described lower levels of emotional awareness in individuals on the autism spectrum, this finding was not evident across all the cases in this study. Rather, many of the young adults showed significant awareness and analysis of the emotional experiences that they had had, and the ways in which these experiences had impacted on their wellbeing, including their social and emotional wellbeing. For example, Eric spoke in depth regarding the emotional complexities of both considering himself asexual while simultaneously wanting a partner. Piper spoke of the emotional difficulties associated with managing the complexity of everyday living, work, study and relationship expectations, and the emotional difficulties that this caused for her, while Tamara spoke eloquently about the importance of and the need for emotional connection, support, and reciprocity in friendships. Conversely, participants such as John, Bruce and Paul spoke less about the complexity of their lives and relationships, instead keeping their responses to short, simple replies. For this research study, it appeared that the participants who used more complex verbal speech discussed their emotional self-awareness in greater detail. This, in no way, assumed that those participants who replied with shorter answers were less aware, but only that they did not communicate this at the time of the interview.

Additionally, all the young adults also spoke confidently about what they perceived themselves as being good at, highlighting both their strengths and their areas of need across a range of life domains, including emotional wellbeing. For example, Anne spoke about her increased anxiety but also about the importance of self-advocacy in dealing with this. Similarly, Paul spoke about the important role that his active engagement in the community through the local social media weather group had on his wellbeing. Each of the examples provided across cases endorsed the key roles of support and resilience for young autistic adults in managing their overall wellbeing.

6.4. Social Participation and its Connection to Transition Practices

6.4.1. Interpersonal Relations

The QoL domain of interpersonal relations considers the relationships that the individual undertakes with family and friends, the types of activities that the individual does with family and friends, and the type of support that the individual receives. Most participants expressed that they had ***positive relationships with family and received significant supports from family***. Furthermore, these close relationships could be seen between the young autistic adults and their parents during the interviews where the parents were present. This was displayed through the sharing of stories and humour and through the support provided to the young people as they engaged in the interview. For example, Piper made several humorous comments aimed at her mother, such as, when talking about having children and travelling, she said, “I’ll just leave them with her!” Frank, on the other hand, expressed a need for his family’s assistance while at the same time expressing his desire to be independent from them. Frank perceived his family’s support as both unwanted and necessary, with this conflicted theme running throughout the interview (see Section 5.3.1). Similarly, Tamara described a close relationship with her family, while at the same time feeling that they did not understand her. This perception was evident in the example of her family members wanting her to concentrate on her driving while also engaging in conversation with them. Despite these small difficulties, all the participants experienced a considerable amount of their positive interpersonal relationships through their family, and each described close relationships with their parents, siblings, and extended family and described the various activities in which they participated with their family. These findings were similar to those found by Mattys et al. (2018) and Taylor et al. (2019), with the young adults in these studies also describing the key roles that their families played in terms of their support for interpersonal relations and across other domains.

Friendships were also important; however, the participants emphasised that a ***small number of close friends*** was their preference. The area of friendships was one where the young autistic adults and their parents expressed less agreement in terms of QoL. While parents were concerned about the small number of friends with whom their young adult engaged, the young adults themselves shared that this was intentional and satisfactory. For example, both Piper and Tamara described how they had learned the value of true friendship rather than the need to have a lot of friends. The participants also shared that they did not need to spend a lot of time with their friends or to be with their friends personally. For example, Eric, Helen, and Paul all spoke about their preference to engage with online communities and friendships, even though their parent questioned the ‘genuineness’ of this type of friendship. These descriptions by the participants in this research study were supported by the findings by both Mattys et al. (2018) and Smith et al. (2019). That is, the assumption that more friends and more time spent with friends result in a higher QoL does not necessarily represent how autistic individuals experience friendships. Rather, autistic individuals often prefer to spend limited time with good friends, while also ensuring that they have time to be by themselves. This difference between the autistic and nonautistic experience of interpersonal relations is critical to understanding the QoL of individuals on the autism spectrum (Fletcher-Watson et al., 2019; Pellicano et al., 2019).

Some participants in this study indicated significant difficulties in developing and maintaining friendships. Frank stated, “I find it almost impossible to make friends”, and Helen described how she was not able to maintain her school friendships after transitioning from school to adulthood. Again, this is a key finding of many research studies (Crompton et al., 2020; Mattys et al., 2018), that young autistic adults struggle to develop and maintain both friendships and intimate interpersonal relationships. However, the complexity of this finding has also been suggested across multiple contemporary research studies (Morrison et al., 2020; Sasson et al., 2017), and the role of environmental impacts on interpersonal relationships for these individuals is beyond the scope of this research. Certainly, both the young adults who shared difficulties in this QoL domain showed that they could have positive interpersonal relations with families, and they displayed positive communication and social skills with me, the researcher, during the interview process, providing recognition of the multifaceted complexity of this domain.

Other participants shared the strategies that they had developed to be able to make and keep friendships. Eric described how he used the skills that he had developed in public speaking to learn how to maintain conversations, while Piper described how she had had to change her behaviour to become “me but liked” when she entered secondary school. These descriptions of a more structured, prescribed way of interacting with people and of engaging in everyday conversations were again similar to the descriptions shared by individuals on the autism spectrum in previous research studies (Crompton et al., 2020; Mattys et al., 2018), however, the negative impacts that this type of social masking can have on emotional wellbeing over time is becoming more understood (Cage & Troxell-Whitman, 2019; Hull et al., 2017). Hence, there is a constant tension between the need to establish a sense of relatedness with others and, at the same time navigating the different experiences of interpersonal relationships with others (Morrison et al., 2020). From the descriptions provided by some young adults in this research study, Eric, Piper, Tamara, Helen and Anne, an understanding of their different individual experiences of friendship and the strategies that they used to mediate these differences was critical to maintaining both friendships and emotional wellbeing.

In this research, most participants expressed that they did not have an intimate partner, with some stating that they had ***difficulties with intimate relationships***. The parents of the young adults also indicated that they had significant concerns about whether their young adult would ever find an intimate partner, and how they would navigate the complexities of this. Frank indicated his desire to find an intimate partner on numerous occasions, while his parents explained the social difficulties that seemed to be preventing this. Eric described how he identified himself as asexual, and that he had not yet worked out what this meant for him, although he did indicate that he would still like to find an intimate partner with whom he could share his interests. Research about autistic individuals and intimate relationships consistently shows that this can be an area of difficulty, with many individuals struggling to find and maintain intimate relationships (Cheak-Zamora et al., 2019; Mattys et al., 2018). In this research, two participants talked about their positive experiences with an intimate partner. The first was Tamara: although she and her boyfriend had recently broken up, she still regarded him as a good friend. The second was Piper, who described her partner as “my rock”. The inclusion of these examples is important to show the possibility of autistic adults forming long term, intimate relationships when they find a partner who is understanding of their experiences (Cheak-Zamora et al., 2019; Hancock et al., 2020).

6.4.2. Social Inclusion

Social inclusion is a key aspect of the social participation factor in QoL. Social inclusion relates to how much individuals feel connected to their local community and to how easy it is for those individuals to access the organisations and resources within their local community. The participants in this research study had a variety of perceptions about their social inclusion, and the participants used ***both natural and supported social inclusion***. Supported social inclusion for people on the autism spectrum refers to formal, structured support for the individual to access community resources and organisations. In Queensland, supported social inclusion is most often provided through access to funding from the NDIS (National Disability Insurance Agency, n.d.). The individuals and/or their family then use funding provided through the NDIS to employ a support worker to accompany the autistic individual to access resources and organisations that are required or chosen. Examples of supports provided include assistance with transport, shopping, attending medical appointments or attending community-run social gatherings or sporting clubs. Flexibility with the types of resources accessed is most often associated with the amount of funding available to the individual, the determination of the individual’s needs by the individual and the family, and the areas of interest expressed by the individual (Cowden & McCullagh, 2021).

Five of the research participants accessed supported social inclusion through the NDIS. For some, this was a positive experience where the young autistic adults were able to participate in activities that both they and their parents valued. For example, John accessed a support worker through NDIS who supported his inclusion in regular activities in which young men typically take part. Both John and his mother spoke about the positive relationship that John had with his support worker and the value that this provided for his social inclusion. Helen also spoke of the significant value that being able to access an occupational therapist had meant for her social inclusion. For some young people, the limited options provided result in a less than ideal form of social inclusion. For example, Bruce and his mother spoke about his attendance at the community access group in his local community, with his mother stating, “He hates it. He calls it ‘kindergarten’.” Thus, supported social inclusion can be perceived as positive or negative, depending on the options available and the interests of the young person (Claes et al., 2012).

Natural supports are those supports that exist already in the community or the social circle of the young people themselves. Natural supports are recognised as the most effective form of support as they are not reliant on the provision of funding, they are more inclusive, and they allow a more natural experience of social inclusion by the autistic individual (Bishop-Fitzpatrick et al., 2018; Claes et al., 2012). Natural supports can include support from family and friends as well as from within an organisation. Those participants in the research study who accessed social inclusion through natural support spoke positively about such support and the role that it played. Eric spoke about the close relationship that he had with one friend who was “extroverted” and described how his friend encouraged him to access typical interactions within his community. Similarly, John talked about his friends and the various activities in which he participated with his friends such as going out for dinner and going to the gym. Paul spoke about his connection to the community through his local social media weather group, and Tamara shared the importance of the social gatherings with the coffee group.

All the participants in this research study described a high level of social supports, including either formal or natural supports, or a combination of both. The majority of these was provided through family, with some provided through friends, and some through organisations. Results from a study conducted by Bishop-Fitzpatrick et al. (2018) showed that social supports provided a significant direct effect on the perceived stress on QoL in adults on the autism spectrum. Thus, it can be interpreted that the high levels of social support provided contributed to the overall positive perceived QoL expressed by the participants in this research study. Furthermore, the provision of appropriate support enhanced the functioning of the individual, which in turn, allowed for greater access to social inclusion and natural supports (Claes et al., 2012).

6.4.3. Human and Legal Rights

The concept of human and legal rights within the QoL framework (Schalock & Verdugo, 2002) emphasises individuals seeing themselves as accepted and respected members of society who have the right to live the life that they choose. The participants in this research study focused on key aspects of their perceived acceptance and respect in society. The first was ***identification with the autistic community***, followed by **r*ight of disclosure***, and ***self-advocacy***. Most participants, and their families, spoke about the importance of identifying as an autistic person, but that being an autistic person should not be seen from a negative viewpoint (Bottema-Beutel et al., 2020; Pellicano et al., 2019). Piper talked openly about the positive change in acceptance for being autistic, stating that “Many people, like influencers are coming out and saying, ‘I’ve got ASD, or I’ve got ADHD’, and I like that because it normalises it.” She stated, “It [being on the spectrum] doesn’t always cause problems.” Helen also spoke about identifying as an autistic person who has specific strengths, interests, and differences from nonautistic people, but she added that accepting this as part of who she is and making connections with other autistic individuals are an important part of overall wellbeing (Crompton et al., 2020; Morrison et al., 2020). She felt that being with people who really understand her is a benefit for autistic individuals, similar to the findings by Morrison et al. (2020) and Crompton et al. (2020).

Within these discussions, however, was the key point that it is the individuals' right to choose when, and to whom, they disclose their diagnosis. Tamara felt that at times disclosure of her autism helped others to understand her more, while at other times it meant that they thought less of her and would treat her differently. Therefore, Tamara felt that people should get to know her first, before she would tell them about her autism. Similarly, Piper talked about situations where disclosure of her diagnosis allowed her to be provided with the support that she needed; however, as with Tamara, she did not want to be treated differently or seen as less because of her diagnosis. The right to disclose their diagnosis, and the expectation that their autism is seen as a form of difference rather than as a problem, are common themes described by autistic adults. Furthermore, the difficult decision around disclosure and its possible implications occurs across all areas of life:

employment, education, interpersonal relations, and community engagement (Frost et al., 2019; Romualdez, Heasman, et al., 2021; Romualdez, Walker, et al., 2021).

Many participants also indicated the importance of self-advocacy, which according to the understanding of the participants in this research study included being able to let people know what their needs were and asking for help when needed. For some participants, this was something that they were comfortable doing, while others discussed how they could self-advocate with some people such as their family but found it more difficult to do so with others. John, Bruce, Paul, Helen, and Frank all talked about their confidence in letting their families know what they wanted to do and in asking for help if it were needed. On the other hand, a smaller group, Anne, Eric, Tamara, and Piper, described their ability to advocate for themselves both within their family and with others outside their close social circle. For example, Anne spoke about her willingness to speak with teachers at her school and stated that she was confident that she would be able to let her university lecturers know if she needed support for her studies. Piper also discussed her advocacy in both her university studies and her work situations, while Eric talked about the importance of learning how to speak up about his needs as he had become an adolescent. All four, Anne, Piper, Tamara, and Eric, however, also indicated that this was something that could result in high levels of anxiety and that, at times, they may need support to advocate for themselves (Spain et al., 2018; Ward & Webster, 2018). Frank and his parents, on the other hand, spoke about the difficulties that they had experienced trying to advocate for Frank and about his experience of autism with outside people who “just don’t understand” (see also Pfeiffer et al., 2017).

6.5. Independence and its Connection to Transition Practices

6.5.1. Personal Development

There were two themes identified in the domain of personal development. These were the ***importance of strengths and interests,*** and ***high levels of family support in personal development***. For all the participants in this research study, the importance of strengths and interests came through as a key indicator to facilitate continued personal development both within the school context and when the young person had transitioned to post-school options (Lorenz et al., 2016; Ward & Webster, 2018). Regardless of the post-school option chosen, the young autistic adults continued to follow their own path to personal development if it were located within their strengths and interests. In fact, this research showed that young autistic adults experience high levels of intrinsic motivation to learn and develop when they are following their strengths and interests (Deci & Ryan, 2017).

Examples of this were reflected across the participants in the study. Eric showed high levels of intrinsic motivation for study at university in physics, his area of interest. Interestingly, Eric had since identified that his real interests and strengths were based on learning new information of any kind. He had applied this strength and interest to university study in teaching, as he described how he found the study of the human mind and learning to be just as interesting as physics. Paul, in a different example of post-school options, had never studied at university because he found this too difficult. Despite this inability to follow formal study, Paul showed incredible resilience in his personal development through the local community social media weather group that he and a friend had established. To achieve his goal of establishing the Facebook page, Paul had attended TAFE to study information and communication technologies and to learn how to work effectively with computers and the internet. He continued developing his skills over the years, working with his friend, so that he could continue to follow his strength and interest in weather, and, in turn, used this interest to maintain strong connections with his community.

Examples were also provided throughout the research study where young adults who were not able to follow their strengths and interests experienced low or poor levels of intrinsic motivation and wellbeing. Helen described her experience of working in aged care so that she could “get a job” when her real strength and interest was in art. She identified low levels of motivation and difficulties following directions, and she experienced overall poor emotional wellbeing when engaged in an activity that was not of interest to her (Anderson et al., 2021). Once Helen and her family had identified this and Helen began to engage with art again, she and her mother described how her overall wellbeing and social participation improved. Together, these examples provided support for the theory proposed by Ryan and Deci (2017) that engaging in areas of high intrinsic motivation that are based on high autonomy and competence leads to overall positive wellbeing.

An important aspect of the young adults in this research achieving their goals in personal development, whether it be attending university or TAFE, obtaining their driver’s licence, following a passion, or learning daily living skills, was the high levels of support provided by families in helping the young person’s achievements. The types and levels of support varied significantly with each individual and his or her family; however, all the young adults acknowledged its importance in being able to achieve what they wanted. This finding has been sustained across much of the research (Taylor et al., 2019; Ward & Webster, 2018), with families recognised as key enablers of personal development.

6.5.2. Self-determination

Self-determination is the final domain within the QoL framework that was investigated in this research study. It is important to acknowledge here that self-determination is not a single construct, and, as such, that every other domain influences the level of self-determination experienced by individuals, including the young autistic adults who participated in this study (Ryan & Deci, 2017, 2020). The two themes identified in this study relating to self-determination were that the young autistic adults experienced ***high levels of perceived self-determination***, and that these high levels of perceived self-determination were supported by ***high levels of family support for self-determination***.

Self-determination, autonomy, and personal control were not perceived by the young adults, or their families, as the young people functioning completely independently of their families and support structures. Instead, high levels of self-determination, autonomy, and personal control were seen to exist because of the support received through their families (Hagiwara et al., 2020; Mattys et al., 2018; Ryan & Deci, 2017). The young adults in this research study acknowledged that their families knew them very well, and that their families worked very closely with them to support their level of independence in adult life. Piper, who lived independently with her partner, worked in a non-supported job, and studied at university, spoke often about the role that her family still played in allowing her to continue to achieve these things. Furthermore, she also admitted to the challenges that she faced when trying to do something on her own without engaging family support to do so.

Thus, as opposed to the view that young adults must cut ties with families and live their lives completely separately, the findings from this research study supported Ryan and Deci's (2017) assertions that autonomy, competence, and relatedness are supported by close and continuous connections with others who know the young adult well and who work towards their best interests. Families, for these young autistic adults, were strong advocates for the choices that the young adults wanted to make. Moreover, the family and the young adult worked together to identify and support the young adult's abilities and circumstances so that gradual increases in self-determination were possible. These findings were similar to those of Taylor et al. (2019), who showed the important role that families played in supporting and extending the self-determination experienced by young adults with intellectual or developmental disabilities.

It would seem that, in the case of young adults on the autism spectrum, there are some differences in the role that family plays in supporting the young adults' self-determination; however, this should not be considered as limiting self-determination for the individual. In the cases of Bruce, Frank and Paul, the level of support required had continued well into adulthood. Thus, for some young autistic adults, support may continue for much longer into adulthood, and indeed throughout adulthood, than for their nonautistic or non-disabled peers (Cheak-Zamora, Teti, Peters, et al., 2017; Mattys et al., 2018). However, before this is labelled as an indicator of limited self-determination, the complete picture of self-determination must be considered: autonomy, competence, and relatedness. For young adults on the autism spectrum, the need to meet all three basic psychological needs is paramount for overall wellbeing and must be balanced with the different ways in which autistic individuals experience the nonautistic world (Sheldon & Niemiec, 2006). In this way, the supports provided by and through family provide a more balanced experience of autonomy, competence, and relatedness, thus providing the optimum opportunities for young autistic adults to experience independence, autonomy, and personal choice.

6.6. Key Findings Regarding Quality of Life for Young Autistic Adults

Considering the findings across the QoL domains, key findings were found and are addressed below. These findings included that, across cases, most young autistic adults perceived their QoL as positive, although all experienced some difficulties across a range of domains. Family and outside support were critical for supporting a positive QoL as the young adults transitioned from school to post-school options. The recognition of, and the inclusion of, strengths and interests of the individuals contributed significantly to their overall QoL across domains. Autistic adults showed high levels of resilience as they navigated the transition to post-school options. When faced with poorer QoL within a domain, they showed a willingness and an ability to make different decisions, albeit with support, to achieve more positive QoL. Each key finding is addressed in further detail below.

6.6.1. Perceived High Quality of Life

Most participants in the research study shared a mostly positive perception of their QoL across domains – wellbeing, social participation, and independence. This finding was consistent with more contemporary research such as that conducted by Bishop-Fitzpatrick et al. (2016) and Hong et al. (2016), who found that individuals on the autism spectrum reported their QoL as being higher than that completed by proxy reports. This positive outlook appeared to be closely related to the high levels of autonomy, competence, and relatedness that the individual participants experienced across domains. That is, those young adults who shared experiences related to their autonomy, or volition of action, competence, or ability to complete the skills needed, and relatedness, or high levels of connectedness and support from others, experienced higher levels of both self-determination and QoL. As suggested by Ryan and Deci in their studies of SDT, meeting all three basic psychological needs will support the perceived wellbeing of the individual (Ryan & Deci, 2017).

The one young adult who expressed a less positive view about his QoL was Frank. Frank did view his QoL as positive in many aspects but simultaneously he expressed high levels of conflict within each domain. This conflict was evident where there was one or more basic psychological need that was not, or had not been met (Ryan et al., 2006). For example, while Frank wanted to live in his own home, and he experienced a level of autonomy in sharing this goal, Frank's parents felt that he did not currently have the daily living skills, or competence, for this to be done safely and while also maintaining his wellbeing. The conflict between autonomy and competence was a common area represented across the QoL domains for all the participants in this study. While many would have liked to have complete autonomy in their lives, they did not necessarily have the competence to manage this in a way that would maintain their material, physical, and emotional wellbeing. For example, while Frank would have liked complete autonomy and choice over all aspects of his life, both his parents and he acknowledged that this would most likely lead to poorer QoL and self-determination in the long run.

It has been noted that young autistic adults often express strong but contradictory messages and themes in their interviews (Smith et al., 2019). Frank's interview was an excellent example of this and showed a high level of conflict between desired autonomy and independence, and the competence to achieve this safely. For many of the participants, including those who had high QoL and self-determination, there was a recognition that they needed to work closely with their families and support people to ensure that they were developing the competence needed across daily living skills to continue moving forward with their QoL and self-determination (Baker et al., 2021; Duncan et al., 2022). This, in turn, brought in the concept of relatedness (Ryan & Deci, 2020) and the volitional choice of the young adults to work closely with their families as they transitioned to post-school options. Importantly, the construct of autonomy could still be met under these circumstances as it was the young adults' choice to work with their families and to maintain a high QoL, rather than to move to complete independence at the expense of their QoL in other domains (Ryan & Deci, 2020).

6.6.2. Perceived High Levels of Stress and Anxiety

Throughout the research, all the participants and their parents described the ***high perceived levels of stress and anxiety*** experienced by the young autistic adults. Although the environments and situations that caused these high anxiety levels, and the ways in which these high levels of anxiety were expressed varied, high anxiety was a crucial aspect of the perceived emotional wellbeing of all the participants. The descriptions of the participants' QoL referenced both high anxiety and the strategies that they developed, or the support required, to manage this anxiety. John's mother described his "ever present anxieties" and the resultant "high heart rate" that he experienced. Frank and his parents spoke about the high levels of anxiety that he experienced in relation to his difficulties with interpersonal relations, while Piper spoke about experiencing "meltdowns and panic attacks". Eric described the social anxiety experienced when he must use the phone to make phone calls, and Helen stated that she stayed "just in the house" in response to her anxiety. Research has consistently shown that that anxiety is a significant area of challenge for people on the autism spectrum (Hong et al., 2016; Howlin, 2021; Smith et al., 2019), and the participants in this study supported this finding.

Moreover, Smith et al. (2019) also found that individuals' resilience to stress, including with the supports provided, can significantly influence their perceptions of their overall wellbeing. This finding was important in the present research study as it was evident during the interviews that the young autistic adults in this study experienced ***high levels of family support to manage their perceived anxiety/stress***. Family support was critical to managing the young autistic adults' anxiety and perceived stress, and to helping them to develop and utilise appropriate strategies. All nine participants spoke about the significant emotional support provided to them by family, and the important role that this played in keeping their anxiety and stress levels at a manageable level. John described the strategies that he used as "taking deep breaths and ringing the taxi company", while his mother talked about buying him a Fitbit to help him to recognise and track his periods of high anxiety. Frank and his parents both spoke about his use of physical strategies such as walking, running, and jumping to reduce this anxiety, as well as seeking medical support if Frank's anxiety levels were too high. Helen, and Anne's mother, and Piper's mother, all spoke about “being there”, “finding suitable supports” and encouraging strategies for their young adults.

As suggested by Smith et al. (2019), when stress or anxiety levels increase beyond the limits of the individual and there is no mechanism, such as family support, to balance this, perceived emotional wellbeing may decrease. Thus, while the young autistic adults in this research study experienced high levels of stress and anxiety, the emotional support provided by family and others prevented this stress or anxiety from reaching critical levels and helped the young people to develop and use strategies to manage their high levels of stress and anxiety.

6.6.3. High Levels of Family Support

Across all the cases, and within all the QoL domains, family support featured as a key theme throughout the findings of the research. This was consistent with previous research that showed that most young autistic adults rely heavily on the support of their families across all QoL domains as they transition from school to post-school options (Kirby et al., 2020; Mattys et al., 2018; Taylor et al., 2019). This support is usually in the form of the young adults continuing to live with their families, relying on the family for financial support and/or advice, support for tertiary study and employment, and relying on the family to support interpersonal relations and social inclusion. Objective measures of QoL have interpreted the involvement of the family in the young person’s life as an indication of a poorer QoL, with lower levels of wellbeing, social participation, and independence (Bishop-Fitzpatrick et al., 2016). With subjective measures of QoL, these outcomes are the perception of the individual and not compared against behavioural norms. Thus, perceived QoL can be much higher, regardless of the individual’s specific circumstances.

In this research, examples were shared to indicate that high levels of family support can result in high perceived QoL across all QoL domains. There is no question that the level of family support that was provided to the young adults throughout the transition to post-school options maintained, and in many cases, enhanced the level of wellbeing, social participation, and independence experienced by the young adults. Under the umbrella of SDT, the way that support has been implemented and structured is most important to the young adult's overall QoL and self-determination. Thus, the level of support provided to a young autistic individual need not be an indication of poorer QoL; rather it is the type of support provided by the family that seems to be the difference.

Ryan and Deci (2017) contended that the three basic psychological needs – autonomy, competence, and relatedness, must be met to achieve self-determination showed that self-determination and QoL constructs are closely aligned. Thus, if family support is provided in a way such that it strengthens autonomy, competence, and relatedness, QoL will be enhanced. This can be achieved by providing supports that allow the young adults to work towards what is important to them, in a way that develops their own levels of competence in the areas that matter, and to understand what relatedness means to the young people. In this way, it could be that having the significant support provided by family could lead to a high QoL and to high self-determination for young adults on the spectrum.

6.6.4. High Levels of Outside Support

Moving from family supports to community supports is a natural progression for any young adult transitioning from school to post-school options, and for young people on the autism spectrum this is also the case. Both structured supports and natural supports have been suggested to be important for supporting overall QoL and self-determination in young autistic adults. For the participants in this research, both types of support were evident, to varying degrees, for each young adult depending on her or his level of need. For some young adults, such as John, Frank, Helen and Bruce, the role of structured support provided through NDIS funding provided positive avenues through which new skills were learned and new relationships were formed (Cowden & McCullagh, 2021). For Paul, Tamara, Eric, and Anne, more natural community supports provided these opportunities. For example, Paul accessed considerable support through the local autism support group and through the local social media weather group. Tamara obtained supports through coffee meetings, a religious youth group, and friends, while Eric appeared to rely primarily on friends and family for these supports. In terms of self-determination, as with family support, the provision of support did not detract from the individual's self-determination, provided that the supports were volitional, and valued, and provided environments for further opportunities to meet the three basic psychological needs. It is also important to note that, although outside supports featured heavily in the lives of the young adults in this research, in most cases it was the families who had instigated many of these outside supports. Importantly, moving from family specific to more structured and natural supports presented as a critical part of the process of moving towards self-determination by allowing the development of autonomy, competence, and relatedness across different contexts (Taylor et al., 2019). This suggested that families were conscious of enhancing self-determination and QoL for the young adult through the instigation of both structured and natural supports.

Claes et al. (2012) emphasised the role that individualised supports play in enhancing the functioning of the individual, and they showed that the availability of natural supports has a significant impact on QoL related outcomes. Perceived stress was associated with lower QoL in adults with autism, while high levels of support were linked to reduced stress and thus to higher QoL (Bishop-Fitzpatrick et al., 2018). Thus, improving social supports and decreasing perceived stress are shown to improve QoL for adults with autism.

In this discussion, the construct of support needs was based on the premise that "human functioning is influenced by the extent of the congruence between personal capabilities and expectations, and the environment in which the individual is expected to function" (Claes et al., 2012, p. 97). As discussed in SDT, there is a misunderstanding that the autonomy relates to a lack of needing support. For autistic individuals, this understanding of autonomy, and the coexisting need to reduce support, often result in a perceived lower QoL. As can be seen through the findings of this research, and through its link to SDT and the construct of autonomy, higher support was more likely to lead to higher autonomy and to increased QoL.

6.6.5. Support for Families

Given the high level of family support provided to the young adults, and the key role that family played in accessing structured and natural supports within the community, support for families was another key aspect identified through the analysis. Most parents, in their interviews, shared the lack of support provided to them in finding and accessing supports for their adolescent or young adult. Helen and Anne’s mother shared the lack of information provided to her as a parent, both from the school and from outside agencies: “We were given no information”; “Unless you know what you’re looking for, you just … you don’t know”. Throughout her interview, there were numerous occasions where Helen and Anne’s mother referred to resources that she did not know existed until much later in the girls’ experience or that were of little help. Similarly, a critical feature of the interview with Tamara’s mother related to the perceived lack of support available to Tamara and her because of their residence in a small regional town. She stated, “There was nothing really available and it was very trying to have to drive to [the regional city] on a regular basis. There’s not a lot available here.” Her experience was that “There are services now that we didn’t have when we started out”; however, when services were provided, “All I got out of that, was there were people worse off than us”. Bruce and John’s mothers, however, both shared that they became the “experts” in supporting young people on the autism spectrum, and most often found themselves providing support to others. Thus, although parents and families provide significant levels of support for their adolescent and young adult on the autism spectrum, both throughout school and after school, there is little outside support provided to families. This is, regrettably, a consistent experience for autistic individuals, and their families, across most communities in Queensland (Hatfield et al., 2018).

6.6.6. Strengths and Interests

Throughout the interviews with all the participants and their families, the importance of the individual’s interests and related strengths could not be overstated. All the participants spoke openly and often about their interests and about how this related to the areas where they experienced the highest QoL and self-determination. For example, the main theme throughout the interview with Anne and her mother was that it was when Anne was “true” to her interests and followed “what she loves” that Anne had positive experiences across all QoL domains and achieved a higher level of self-determination. Similarly, a clear connection existed between the more positive aspects of Paul’s QoL domains and his love for, and his capabilities in, following and predicting the weather. Paul’s positive emotional wellbeing, social participation, and self-determination were tied primarily to his interest and “work” in weather and to his sharing of this strength with his local community. Paul's local social media weather group is highly respected in the community and allows him to experience autonomy, competence, and relatedness across QoL domains.

These findings were a replication of the significant amount of research that indicated that many people on the autism spectrum had specific areas of strength and interest (Howlin, 2021). Furthermore, engaging in these strengths and interests has been shown to provide support for wellbeing, social participation, and independence across the lifespan for autistic individuals. Wood (2021) showed the value of providing personalised instruction based on an individual's strengths and interests in the context of school, with students involved in their interests being more engaged, achieving higher academic outcomes and experiencing an improved sense of connectedness at school. Similarly, Anderson et al. (2021) found that young people believed that employment based around the strengths and interests of the autistic individual resulted in higher job satisfaction, while Ward and Webster (2018) identified that autistic university students experienced more success with their postsecondary studies when studying in an area related to their strengths and interests. Finally, research has shown that engagement with strengths and interests results in improved interpersonal relations and social inclusion for people on the autism spectrum (Grove et al., 2018).

6.6.7. Resilience

It is important to note that the positive perception shared by the young adults across their QoL domains did not mean that none of the young adults experienced any difficulties in their transition to post-school options. In fact, all the young adults in this research shared difficult experiences that they had had in the past or that they were currently experiencing. These difficulties included relationship problems, difficulties finding and maintaining valued employment, and difficulties finding acceptance within their community. Despite these significant difficulties, all the participants spoke about their resilience in overcoming these difficulties, as well as about their goals and aspirations for a positive future. Autistic individuals have often been seen to lack resilience (Clark & Adams, 2022); however, this was certainly not the case for these young autistic adults, and the high level of resilience showcased throughout this research group was heartening to see.

Resilience is described as “the capacity to experience better than expected outcomes despite adversity” (Clark & Adams, 2022, p. 2). Resilience has typically been regarded as an innate ability, something that one either has or does not have, yet contemporary research suggests that resilience involves a combination of individual characteristics and supportive environmental conditions such as positive family relationships and appropriate supports (Clark & Adams, 2022; Onyishi & Sefotho, 2019). Furthermore, resilience is considered a dynamic process, suggesting that the level of resilience experienced by an individual can vary across contexts and situations (Montgomery et al., 2008). Thus, supportive contexts, such as high levels of family support, can provide the context in which autistic adolescents and young adults can develop resilience to face the adversities experienced during the transition from school to post-school options. Based on the findings of this research, effective and involved family support is important in the development of resilience for young adults with autism (Lai & Szatmari, 2019; Montgomery et al., 2008). Continued family support reduces the negative outcomes of risk factors such as difficulties with budgeting and developing appropriate social relationships, while at the same time allowing the young person to experience natural consequences and to develop appropriate strategies (Muniandy et al., 2021). Thus, high levels of autonomy and relatedness together provide an environment in which the young autistic adult can develop resilience.

This link among SDT, relatedness, and resilience was supported by Perlman et al. (2017), who found that higher levels of relatedness significantly predicted resilience in people with a lived experience of mental illness. Although their research was not conducted specifically with young autistic adults, there were significant similarities of experience, including the significant challenges, faced by both groups. The findings of this research indicated that personal and family relationships and support, as well as general social inclusion, play a significant role in resilience and in developing the ability to cope with the adversity experienced by young people. Moreover, considering resilience approaches to supporting QoL and self-determination during the transition from school to post-school highlights the importance of access to supportive resources for both the autistic individuals and their families (Lai & Szatmari, 2019).

6.7. Chapter Summary

Throughout Chapter 6, the key findings of a cross-case analysis of the young autistic adults' perceptions of their current QoL were presented. This cross-case analysis considered the nine individual cases, looking at the similarities and differences across the eight domains of the QoL framework. These similarities and differences were used to support key themes within each domain, and examples were provided from the young adults and their parents to highlight these themes. The key themes presented answered Research Question 1: ***How do young autistic adults perceive their current QoL?***

From the cross-case analysis, it can be seen that the young autistic adults in this research had an overall positive QoL. All the young adults experienced mostly positive QoL in the wellbeing domains, with the main area of difficulty being related to emotional wellbeing. That is, although experiencing positive material and physical wellbeing, all the young adults shared the difficulties that they experienced around increased levels of stress and anxiety. It is important to note that, while sharing these difficulties, the young adults' primary focus was on the supports provided and the strategies used to address this stress and anxiety. Thus, although difficulties were experienced, the young adults shared a more positive than negative level of emotional wellbeing.

Similarly, all the young adults shared the difficulties that they experienced within the social participation domains, although again most shared that they were content with the quality of the interpersonal relations and social inclusion that they currently had. Those participants who spoke about a positive QoL in the social participation domain indicated that they needed only a small number of good quality friendships and strong family connections for this to be achieved. One young adult did share significant difficulties in the social participation domain, with limited friendships, difficult intimate relationships and conflict between himself and his family. Despite this, he did still experience high levels of supported social inclusion and he counted this as a positive aspect of his social wellbeing.

The final domain of independence included personal development and self-determination. All the young adults expressed high levels of personal development in areas of interest to them, and all felt high levels of self-determination, or had high levels of volitional choice in the main aspects of their lives. Importantly, for all the young adults, and across all the QoL domains, family support played a crucial role in the achievement of a positive QoL. Similarly, engaging in their individual strengths and interests contributed significantly to the young autistic adults' wellbeing and self-determination across all QoL domains. A final key finding was that the young autistic adults showed high levels of resilience as they navigated the transition to post-school options. When faced with poorer QoL within a domain, they showed a willingness and an ability to make different decisions, albeit with support, to achieve a more positive QoL. None of the young adults believed that they would not experience any adversity while establishing themselves in adulthood. However, all believed that with hard work and support they could achieve their goals and aspirations.

Each of these findings supported the conceptual framework presented in Chapter 3. That is, SDT and the biopsychosocial model of disability are a relevant umbrella theory through which the QoL of young autistic adults can be considered. As with all young adults, those on the autism spectrum experience higher levels of self-determination and wellbeing when their basic psychological needs of autonomy, competence, and relatedness are met throughout the transition from school to post-school options. Critically, these needs are met when appropriate environmental conditions and supports match the individual characteristics of the young adult.

CHAPTER 7: SECONDARY SCHOOL TRANSITION PRACTICES

7.1. Chapter Overview

The transitions from school to post-school, and from adolescence to adulthood, are recognised as complex processes where multiple factors work together to influence the young person's life after school. With these multiple factors, the role that schools and school practices play is considered significant (Education Council, 2019). Specifically, school practices are expected to be based on ensuring the best post-school outcomes for all students as they make this transition from school to post-school options. The Taxonomy for Transition Programming (TTP) presents a comprehensive, conceptually rich organisation of transition practices through which transition-focused education and services can be developed and delivered (Kohler et al., 2016). It is a framework that provides schools with the critical factors considered necessary to ensure that schools are preparing their young students with the skills, knowledge, and attitudes that will be required for successful transition to adulthood. Although the TTP framework is not mandated in Queensland or Australian schools (Cumming et al., 2020), it is still considered to be best practice for transition-focused education for students with disabilities, including those on the autism spectrum (Beamish et al., 2012; O'Neill et al., 2016). From this perspective, the transitions practices experienced by the young autistic adults were categorised according to the five domains of the TTP framework (Kohler et al., 2016). The five domains of the TTP, and a brief description of each domain, are listed in Table 7.1 Taxonomy for Transition Programming (TTP) Practices.

Table 7.1

Taxonomy for Transition Programming (TTP) Practices

TTP domain	Description
Student-focused planning	Includes the development of student goals, student participation in planning and decision making and student evaluation of their progress in meeting their goals. Through student-focused planning, students develop and strengthen self-determination skills. A key aspect of student-focused planning is that educational decisions are based on student's goals, visions, and interests (Kohler & Fields, 2003).
Student development	Emphasises life, employment, occupational, social, and academic skills to enhance opportunities for graduation and gaining employment. This involves identifying accommodations or supports a student needs to participate and achieve success in educational, employment, and community settings (Kohler & Fields, 2003).
Family involvement	Parent and family participation in planning and delivering education and transition services. There are three aspects of family involvement: • Participation – a wide array of involvement such as assessment and decision making • Empowerment – practices that facilitate meaningful family involvement by identifying family needs • Training – increases family members ability to work effectively with others. Student-focused and student development strategies are supported and extended through family involvement (Kohler & Fields, 2003).

TTP domain	Description
Program structure	"The structures and attributes of a school provide the framework for implementing transition-focused education" (Kohler & Fields, 2003, p.179). Clearly articulated mission and values, qualified staff members and sufficient allocation of resources.
Interagency collaboration	Collaboration between community businesses, organisations, and agencies in all aspects of transition-focused education. The purpose of interagency collaboration is to "implement an integrated system that addresses the lifelong learning and support needs of a community's members" (Kohler & Fields, 2003, p. 178). When done well, it facilitates achievement of transition goals, when done poorly, it limits or impedes those transition goals.

7.2. Introduction to the Participants and their Schooling

Nine young adults and their parents were interviewed for this study with a range of characteristics and experiences represented within the group (see Appendix Q). There were five males and four females interviewed, six were between the ages of 18 and 25 years, and three participants were between 26 and 39 years. Two participants were attending university, and six participants were employed (see Table 6.1). Of the participants interviewed, three lived independently, while the others lived with their families. Three of the participants received moderate to high levels of National Disability Insurance Scheme (NDIS) funding and support, two participants received low levels of NDIS funding and support, and the remaining four did not receive any NDIS funding and support. All the interviews were conducted with the young autistic adults and their parents, either together or separately. A range of strategies was used to encourage optimal participation in the interview for all the young adults.

The secondary schools attended by the young adults varied considerably. Four of the young adults had attended a large state secondary school in the region's large inland regional city. There are four such schools in the city and not all young adults had attended the same school, although the sisters, Anne and Helen, had both attended the same school. One of the participants had attended a Christian college in the state's capital city, while two other participants attended Christian colleges located in separate smaller regional towns. One college was located on the state's south-east coast, and the other was located in a small regional town approximately two hours' drive west of the capital city. The final two participants had attended a small state secondary school located in a small regional town approximately three hours' drive north-west of the capital city. Thus, as with the participants, the diverse range of schools attended was considered valuable to represent the range of mainstream secondary schooling options available to autistic students in Queensland. Furthermore, it was hoped that the similarities and differences between this variety of schools and their programs would provide valuable information for all secondary schools.

7.3. John

7.3.1. Introduction

John attended a large regional city secondary school from Year 8 through to Year 12 and graduated from school approximately five years prior to the research. John received support through the special education program throughout his schooling, although John's mother described how he had been "Supported heavily initially, and then they [the school] paired that back. They did that very well", so that John was "Gradually integrated more into the mainstream school."

7.3.2. Student-focused Planning

Student-focused planning was described by John's mother as something that did happen, although she felt that it was not as individualised or student-focused as it should have been. She described how "high school was post-school orientated"; however, the "Actual nitty-gritty of transition planning was mediocre". She went on to state that "I had a sit-down interview for the Senior Education and Training (SET) plan, and John was also present at the SET plan meeting, but it was heavily guided."

From John’s mother’s perspective, “there was a certain condition or direction put forth as far as what post-school options would be available”; that is, “John was given a choice of transition pathway, retail or hospitality.” At the time, “He was participating in hospitality. He did love to cook. I think that made sense for him, that that would be a pathway that he would follow. I think he grabbed that, and that was that.” Interestingly, John’s mother felt that “It was fortunate he showed an interest and strength in hospitality”, because “if his interest had been something less common, it might not have been supported.” John himself did not refer to the SET plan meeting or to the decisions that were involved with this meeting, simply stating that, “Yes, I enjoyed that subject [hospitality]. I did a certificate course online.”

John’s mother went on to describe how “The SET plan was just a one-off event”. “It was a very brief meeting, and I didn't have any ongoing engagement in that space. There were no ongoing conversations around what that might look like in Year 11 and 12 and beyond.” She indicated that “He followed the hospitality pathway and that was his certificate, Hospitality I and II. They [the school] enabled that and provided that as part of his SET plan.” Although John’s mother felt that this transition pathway was the easy option, with no real investigation into what would truly suit John as a future career, or what he would truly love to do. She stated that,

> I wasn’t happy with the hospitality/retail thing. I mean he loved art as well and did very well and followed an art pathway the whole way through. But this was never unpacked as being an option. Maybe he could do art out at the university. That was never discussed. I saw them as quite a similar type pathway as far as programming and his engagement, his abilities, and those sorts of things. I think he'd shown an interest in this [hospitality] and had identified that through the set. That was it.

Furthermore, John’s mother felt that,

> I think had he determined something else as being his chosen pathway in the set plan that wouldn't have been pursued. If he said he wanted to fly a plane or become a pilot, I don't think that that would have been something that they would have done. It would still have been up to us to actually make that happen.

When asked what he loved to do more than anything else, John's reply was, "I would say, drawing." This comment supported John's mother's belief that an art pathway would have been just as suitable as, if not more suitable than, hospitality. Thus, the exploration of different options appeared not to have been addressed in John's case (see also Chandroo et al., 2020), with the school, from John's mother's perspective, choosing the first and easiest option.

7.3.3. Student Development

From John and his mother's perspective, many areas of student development were addressed in a very positive way by the school. John's mother stated, "The school's building of John's self-worth and confidence can't be faulted. It enabled the confidence and the growth we saw through high school." She described how John had followed a typical Queensland Certificate of Education (QCE) pathway that included a range of subjects, including the Certificates in Hospitality: "He followed a QCE pathway. It was the curriculum in the Certificates." John supported this by articulating the classes in which he had participated, "I did art, and I did social group, and I did science, all those subjects", "I did hospitality classes at school", and "I did some reading in school." Furthermore, he talked about how "I learned about money and maths when I was at school", and "I asked for help at school when I had difficulties with maths or computer work." In terms of employment skills, the Certificates in Hospitality were very much designed to provide John with skills that he could use in a future workplace.

Despite these positive aspects, there were areas where the school provided fewer opportunities for learning. John's mother indicated that, in terms of social and emotional skill development, "I don't think so. I don't think there was specific lesson content or purposeful groups made where that was happening." She felt that "I think he did learn it at school, but I think it was just being part of the five years. Plus, I think because of his friendship group. There were six of them there that were as tight as tight." Thus, John's mother indicated that the lack of specific social and emotional skill support was offset by the natural supports provided by John's friends: "Friends provided support at school as well." While John did mention social group in his list of classes, he talked more about the friends he had at school and how important those friendships were. John also indicated about learning how to deal with his high levels of anxiety: “That’s something I’ve learned when I got older. I don’t think I … learned any of that when I was at school.” Thus, for John, the academic skills and employment skills were addressed throughout school, while the life, social, and emotional skills were given less emphasis. Rather these skills were developed through the natural supports of his school friendships (see also Cribb et al., 2019).

7.3.4. Family Involvement

Family involvement was one area of the recommended TTP framework that John’s mother suggested was lacking. While the family was invited to attend a SET plan meeting, she stated that “I didn't have any ongoing engagement in that space.” Interestingly, Beamish et al. (2012) found that “A high level of parental attendance at meetings did not translate into meaningful collaboration.” Furthermore, while family-school relationships were rated by educators as the most highly valued transition practice, practices related to empowering families to lead decision making were less supported. The comments provided by John’s mother depicted a clear example of this. She stated,

> It was more the school did their thing and we were very happy with the school and John was very happy at school. He achieved well and just moved through the grades and we saw this opening and this blossoming and had very limited, probably, engagement with the school from a family perspective because there wasn't any real apparent need.

Although John was doing well at school, his mother admitted that “Probably I just saw the end [of school] coming, so I thought, ‘What do we do here?’ So, we started with the volunteering thing. I made that happen.” “He engaged with the volunteering at one of the local hospitals, all through [the] second half of Year 11 and 12 and continued to do that until Covid put a stop to it. He’d been doing that for more than five years.” She went on to describe how

> We, family, drove the work experience placements while John was at school … We went and met with the volunteer coordinator, and she was very gracious. Took John on and made some lovely accommodations and adjustments to help him in that space initially. He would do that of a Tuesday afternoon instead of sport. Well, they had a free [period], they didn't do sport

> Tuesday afternoon. I would go and pick him up and he would go and volunteer on Tuesday afternoon. In school time.

She reiterated that this was “Completely separate from school. They knew he was doing it, but that was because we just told them that’s what we had initiated.” Thus, the “School didn’t incorporate family initiated and driven experiences into the school program”, “They thought that we were doing something, and it was good, and that was that.”

The importance of this work experience was reinforced when John’s mother went on to share that, “There was a connection from his volunteer work to that [his current employment]. That's how that happened.” So, “I made the job happen really … with people. It’s the relationships you build. It wasn’t just me, but you know what I mean.” Although work experience while in school is acknowledged through research to be one of the key factors in future employment (Pillay & Brownlow, 2017; Wehman et al., 2015), there was limited support for this from the school: “It ran in parallel, but there wasn’t that connect[ion] between school and home. We just made that happen. They did their job. We did ours and it came out in the end.”

7.3.5. Program Structures

John’s mother had many positive things to say about the program characteristics of the secondary school that John had attended. She commented that it was a “supportive school environment” with a “positive school culture”. She also stated that the staff used “positive pedagogical practices”. Furthermore, John’s mother was pleased to see that, while he was “supported heavily initially”, the school staff were able to recognise John’s development and growth, and that he was “gradually integrated more into the mainstream school”. Thus, from John’s mother’s perspective the program structures of the school were generally positive and supportive.

One area that would seem to have been lacking, however, was in terms of the policies and procedures around the transition planning. As stated previously, John’s mother found the transition planning to be “mediocre” and cited repeatedly that their positive experience was more to do with the fact that John’s chosen transition path was a “fairly typical pathway” and that had this been different she did not believe that the same level of support would have been available. John also supported this when asked whether he had been able to make decisions about what he had wanted to do at school, or whether he just had to follow what everyone else did, to which he replied, “Follow what everyone else does.”

This is a significant problem that has been identified repeatedly across a variety of school transition pathways. Chandroo et al. (2020) found that students with disabilities, particularly students with autism, were often offered a limited choice of transition pathways that had little to do with their personal strengths and interests. Furthermore, the term “transition” indicates “a change from one state or condition to another” (Merriam-Webster, 2022). Thus, considering support for transition would seem to indicate that supports would need to be provided across both different states/conditions, to ensure a smooth transition between the two. According to John’s mother, this was not the case. She stated unequivocally that “I think it [the support for transition] ended the day of the last day of school”, and that “John could have just left school … well he did … and they wouldn’t know nor have any idea as to where he was going or what he was doing.” She also indicated that, in her conversations with other families, they also “didn’t sense there was that ongoing support [after school].”

7.3.6. Interagency Collaboration

Interagency collaboration was one TTP domain that both John and his mother rarely mentioned. John’s mother, in response to a question about interagency collaboration, responded with, “They did have people come into the school from employment agencies and have conversations, but that always works to that fairly superficial level.” She also indicated that “We did register with an employment agency. I think that was post-Year 12.” However, this was not a positive experience as John’s mother indicated that this was

> A total lot of wasted time if I’m totally honest. He may still be on their books. I have never received a phone call other than directly from the office just to say, ‘You still happy to stay on?’ … ‘Yes, sure’. He had no idea who they were. Never made contact about anything.

Although not specifically mentioned by John or his mother, from conversations about the Certificates I and II in Hospitality, it can be assumed that the school did work collaboratively with the Technical and Further Education (TAFE) campus to provide access to these certificate courses and that this was recognised as part of John's senior education program. From John's mother's comments about prescribed pathways, however, it can also be anticipated that only specific TAFE courses were offered as part of the senior education pathway through the school.

7.4. Anne

7.4.1. Introduction

Anne attended a large regional city state secondary school and had recently graduated at the end of the year in which she was interviewed. Anne received special education support throughout her secondary schooling. This was provided through the Special Education Program (SEP) as support for Anne to attend mainstream classes. She was provided with a case manager whose role was to liaise with both Anne and her teachers, and to provide advice on how best to support Anne's needs in the educational context. Anne's perception of this support and how it had influenced her QoL can be summed up in the statement, "I've been through hell with school."

7.4.2. Student-focused Planning

Anne and her mother both described the SET plan as a one-off meeting that was, "just subject selection". Neither Anne nor her mother believed that the process supported Anne in her decision about what she would want to do after completing secondary school. In fact, from Anne's perspective, the process was a very negative one that pushed her into a completely different direction from the one based around her strengths and interests. Anne described how "I was pigeonholed into doing something that I didn't want to do. I didn't feel like I had much control over anything at school. When I did my interview in Grade 10, I was saying, 'Yes, I really want to do history. I want to make it a career.' I was basically told that 'History is a (forgive my language) piss poor career. Why would you want to do that? It's better to go into nursing'." For Anne, after the SET plan interview, she felt, "Why do I want to pursue my passion then if it's not going to do much for me?" Anne went on to describe the additional difficulties that she experienced throughout the rest of secondary school based on this interview, and her subsequent decision: "I was pushed towards science subjects and I'm not good at science. I thought, 'Well, maybe I should do biology if that's going to get me into nursing. I failed nearly all my biology assignments'." Furthermore, Anne shared that "It caused me a lot of emotional distress. I tried going to teachers and saying, 'Look, it's not working for me. What can I do?' and they said, 'We don't know. Just deal with it.' That sort of thing." As a result of this, Anne experienced increased levels of anxiety and stress relating to her academic progression throughout her final years of secondary schooling. Fortunately for Anne, as discussed in the previous chapter, Anne's parents convinced her to "stick to" her strengths and interests, and at the last moment Anne changed her application to university from a Bachelor of Nursing to a Bachelor of Arts majoring in History. Anne visibly showed her relief with this decision, with her entire body relaxing as she stated, "I'm hopeful it will be better."

Thus, for Anne, student-focused planning did not occur. While she was involved with the process, there was no preparation provided, there was limited consultation with the family, and it was used to focus not on her strengths and interests, but on what was perceived as a good employment opportunity. This led to increased levels of anxiety and stress for Anne throughout her secondary schooling and had the potential to result in an inappropriate choice of study for university and a reduced QoL throughout her university experience.

7.4.3. Student Development

Student development relates to the use of assessment to underpin decisions, the teaching of academic, employment, life, and social and emotional skills, and the supports provided to the students throughout their schooling that are focused on preparing them for the transition to post-school options. Anne discussed three key areas of student development that, from her perspective, indicated the lack of support and skill development provided. The first of these was in relation to student supports, the second was in relation to social and emotional skill development and support, and the final discussion related to academic and life skills.

Student supports are those accommodations and adjustments the student requires to participate and succeed in the educational setting (Kohler & Field, 2003). Anne described very clearly the lack of support provided to her at school:

> I had to explain to teachers what problems I had, and that should have been in my file already, but they didn't bother looking at it. I had to explain to my case manager this year what problems I had, and even then, she only spoke to me twice this entire year.

She went on to state that "Just explaining it I felt like I was being stupid almost. There's not much to understand about autism. That was the message I was getting from people." During this conversation, Anne appeared very distressed, repeatedly pulling her jumper down over her hands, and twisting and wringing her shaking hands. When I asked Anne if she were aware if her case manager did work with her teachers on the supports and accommodations, Anne emphasised: "Never." At this point in the conversation, Anne's mother suggested that "They have allowed Anne to leave the classroom if she becomes overwhelmed. We did go through the process of getting her extra time allotted for exams, extra time if she felt she needed it for assignments." To which Anne responded, "It's only been with one teacher that allows that. No. If it became too much for me, I'd just put my head on the desk and I'd fall asleep."

This perceived lack of support was also evident in Anne and her mother's discussion about the social aspect of managing at school. Both Anne and Helen shared that they struggled socially and emotionally during break times at school. Anne's mother discussed how they would both come home and talk about these difficulties, so she contacted the school to ask for support. She stated that, "Even when we brought it up to the school, that it would benefit the girls if there was a space that they could go to at lunch where other kids who were struggling as well, where they could all get together. No, nothing. Weren't interested." Anne again chimed in with an example: "I was offered the chance to go into the special education unit [SEU] one day during lunch time, and I went round there. I took the opportunity. No one was there to let me in. I was locked out."

Anne also discussed the significant level of bullying that she experienced during her final years of secondary school. She shared that "The bullying was horrible. I reported a student for swearing at me, so he began targeting me for two years." She went on to state that "I was kicked repeatedly" and shared that the result of this was that "I became depressed. I was sick all the time and I missed out on weeks of school." Furthermore, "When I tried to go to the teachers, and even the school-based police officer, they said to me, 'Oh, he's got problems too. Just leave him alone'." Her frustration with this suggested strategy was that "I can't walk away all of the time. Especially in class." Anne's mother stated that, "Even though we repeatedly asked for Anne to be put in different classes so that they weren't together, as a solution, they were put together. We felt that the school just wasn't backing us up and listening to us." Research conducted by Maiano et al. (2016) showed that adolescents with autism are significantly more likely to experience bullying at school then their nonautistic peers. Moreover, these increased levels of bullying place them at increased risk of developing poor mental health such as depression and anxiety (Ashburner, Saggers, et al., 2019). For Anne, the lack of social and emotional support provided in the face of bullying resulted in her developing depression and experiencing overall poor emotional wellbeing throughout her final years of school. The chance that poor emotional wellbeing at school will in turn lead to poor emotional wellbeing post-school is also highly supported by the literature (Shochet et al., 2021).

A final area discussed was the lack of provision of life skills. Anne stated, "At the school that I attended, where Helen attended, we have life skills, and in these life skills classes we're meant to be taught how to manage money and whatnot. We're not taught anything about that in there. Study skills. We're just taught study skills." Anne went on to discuss the various things that she felt that she would have benefited from learning in life skills classes. This included "how to manage money", "how to make a phone call", "what supports she could access both inside and outside of school" and "how to ask for help". Anne shared that

> Me and Helen struggle with this both, we struggle with asking for help. In my case, it's got something to do with school. I felt like I was being a burden on the teachers if I ever asked for help. They'd get all huffy and puffy if I even dared to ask for help.

Furthermore, Anne felt, “That’s probably the main thing as to why we didn’t get much help. Even in school, ‘Oh, you don’t look like you've got a disability as such’.” Anne’s mother supported this with, “They’re the quiet kids who sit at the back and just wanted to get on with it”, and Anne’s sister Helen supported it with, “We weren’t the squeaky wheels, no.”

Student development, for Anne, was another area of transition programming that was not addressed effectively at the school. While she spoke about her negative experiences with student support, social-emotional support, and learning and life skills, Anne and her mother did not mention what, if any, assessment was completed to determine Anne’s needs across these areas. This corroborated findings by Cumming et al. (2020) that assessment to determine student needs was noticeably absent from discussions by stakeholders, both parents and teachers. This indicated that specific student needs are not being identified through assessment, and thus the supports and skills addressed are not based on assessment of needs. For Anne, this had resulted in significant increases in the levels of depression and anxiety that she had experienced throughout her final years of schooling and the need for her parents to teach life skills, and social and emotional management strategies, at home (see Chapter 5, Section 5.4).

7.4.4. Family Involvement

Although Anne did not speak specifically about family involvement, Anne’s mother expressed her disappointment with how difficult this was. When asked if she were easily able to speak with a school staff member if needed, she replied, “Not really. Not unless I emailed them and said, ‘I need to talk to somebody’.” She did, however, share that

> It’s been better with Anne. If I did approach the school, ring them up, I would have her, well, in Years 8, 9, and 10, I had her case manager on the phone with me that day saying, ‘What’s going on?’ I was able to tell her that Anne has been bullied or whatever. That was really good but in Year 11 and 12, nothing. I would send an email and say, ‘I really need to talk to somebody’, I’d get an email back ‘I can’t today’ or that sort of thing.

This lack of response during the final years of schooling is especially concerning as they were keys years for the implementation of Anne's education and transition plans.

Anne's mother did mention one benefit to home-schooling during Covid lockdowns of the past year with the comment,

> For Anne, this has been a benefit with Covid, because she had to do a lot of the online stuff, she was able to email her teachers all the time. That's kept going. That communication has been really good and then I would jump in and say, 'Oh, just let them know from me that this is happening'. She has taken a lot of that on board herself and has been able to do it that way.

For Anne and her family, however, the only form of involvement had been around the basic day to day communication of issues that were occurring. There was no indication that the school undertook any family preparation or family empowerment regarding Anne's impending transition out of school. This same outcome is a common finding in multiple research studies of family involvement in transition planning for post-school options in Australian schools (Beamish et al., 2012; Meadows et al., 2006; O'Neill et al., 2016). Thus, as is common for most families, Anne's parents had spent the last months, leading up to the transition from school to post-school, trying to locate resources and organisations to support Anne throughout her transition (Kirby et al., 2020).

7.4.5. Program Structures

As with the previous areas of transition programming, both Anne and her mother felt that the program structures within her secondary school did not support Anne's planning for transition to post-school options. Many areas within the program structures were not discussed – for example, program evaluation, strategic planning, policies and procedures, or resource development and allocation. The primary areas of discussion were around program characteristics and school climate. Both areas were considered by Anne and her mother to be very poor, with numerous examples shared throughout the interviews. Anne's perception of program characteristics focused primarily on the perceived lack of support for her as a student, the lack of development of skills and strategies, and the lack of recognition of and support for her strengths and interests (Wood, 2021). Her perception of poor school climate was also based on the lack of support provided by school staff across all areas of her development and wellbeing, and the bullying that she experienced in the last years of her schooling (see also Ashburner, Saggers, et al., 2019).

7.4.6. Interagency Collaboration

Interagency collaboration was also described as very poor by Anne and her mother. Anne's mother spoke about the lack of collaboration between the psychologist whom Anne accessed privately and the school. Although the psychologist was supporting Anne for anxiety and depression, there was little integration of suggested strategies into the school environment. Anne's mother stated, "It would have been beneficial if it had been because the teachers might've been a little more aware of what was actually going on for the girls as they were coming through and what they were going through at school and socially, all that sort of thing." Rynkiewicz et al. (2019) referred to the importance of recognising and supporting experiences of anxiety and depression in girls on the autism spectrum through early diagnosis and support. In the case of Anne, however, despite her early diagnosis, the anxiety and depression experienced by Anne appeared not to be adequately addressed throughout her educational experience.

An additional example shared by Anne was the limited collaboration between the school and university as she planned to transition from one to the other. Anne described the information provided to her as

> Nothing whatsoever. They might have a couple of representatives from the university come out, but they would have nothing on support or anything like that. They haven't taken me out to the university or explained how it is. They've given me an application and said, 'Here's the early offer, the university is thinking about accepting you, please sign it and they'll have a think' … that sort of thing. They haven't been much help.

Anne's mother supported this as she described how,

> It's only been through Anne and I … looking online at the university website that we found the form to download so that she can apply for support

> services. That’s our next step. We’ve got to fill that form in and take it to the doctor and all that sort of thing.

A significant finding of research into the transition from school to university suggests that this is a common experience for students on the autism spectrum (Cai & Richdale, 2016). Information about which supports are available and how they can be accessed is considered critical in supporting successful university experiences for students on the autism spectrum but can be difficult for students and their parents to access (Cai & Richdale, 2016; Thompson et al., 2019; Ward & Webster, 2018).

7.5. Helen

7.5.1. Introduction

Helen attended the same large regional city state secondary school as her sister Anne; however, she had graduated from secondary school approximately five years earlier. Helen was described by her mother as “always struggling at school”, indicating that “There wasn’t a lot of support. Poor Helen really missed out on a lot. I think a lot of missed opportunities with the school.” A contributing factor in Helen’s experience of secondary school was her diagnosis of autism at the age of 14. For Helen, her initial diagnosis was received after her sister Anne’s diagnosis. Helen’s mother shared that, “There were a lot of other issues going on with her, she was depressed and there was a whole heap of other concerns about her at that time as well.” To complicate this further, the diagnosis itself was described by Helen’s mother as having little impact in terms of the support provided to Helen while she was at school. When asked if the diagnosis had helped to improve things at school, Helen’s mother replied,

> No, not at all. She was treated like any other student there. It was just, this is Helen. She happens to have this. She was made part of the special education program but there was no … she wasn’t even assigned a case manager. There was no communication with the special education program at all.

Thus, Helen’s experience of secondary school was one of struggling to manage with little support being offered, while at the same time, struggling to accept her diagnosis of autism. Helen’s mother felt that “It wasn’t until probably even the end of Grade 12 where Helen was quite willing to accept the fact that she had autism.” Helen herself described how “My last two years of school were awful. I just wanted to get away from education.”

7.5.2. Student-focused Planning

As with Anne and their mother, Helen felt that the SET planning process was, “only about choosing subjects for Year 11 and 12” and reiterated the lack of support that the process provided for students trying to decide what they wanted to do post-school. For Helen, there was the added complication of having just received her diagnosis prior to the SET planning process. She stated, “I think it was around that time or maybe the year before I had just been diagnosed, so it was a lot on my plate.” She went on to discuss how difficult it was to work out what she wanted to do with her life when she hadn’t yet worked out “who she was” with her new diagnosis. Helen’s mother elaborated, stating,

> It was the end of grade 10 they had an interview. That was about choosing your subjects for Year 11 and 12 that would lead you into your future. It was a high-pressure situation in front of mum and dad, and one-on-one with a teacher that they didn’t necessarily know … and make a choice about your future in this half-hour session that you had. That was it.

Furthermore, “At this time too, poor Helen was going through all of this drama with being bullied and all this stuff was going on, and she just wanted to get away from education. I think she chose the simplest option for herself at the time.” When asked directly if Helen knew what she wanted to do post-school at this time, she explained, “No. I had no idea. I was in Grade 10 and just trying to get through school.”

Helen also felt that there was no opportunity to move away from this decision later as she moved into Years 11 and 12: “It was just, ‘These are your classes. You’re in this year level. These are the classes you do’.” Additionally, Helen felt that there was “nothing to push us in any direction” and “there was a lack of encouragement as well, especially for kids that had a real passion for something”. Using herself as an example, Helen stated,

> I think what they should do though high school is … and it’s not just for kids on the spectrum … it’s any kid who’s got a talent or got something they’re really interested in. Say for art as a general subject. ‘Okay, so you really like

> art. These are the different career options. These are the types of jobs that are involved in art,' and give them some different ideas on where things could take them, and not just say, 'Art. Oh well, that's nothing. That's a nothing course'.

Helen elaborated that, while her artistic ability was "certainly a strength they recognised", she indicated that "They never really promoted it or anything like that." Helen's mother, in discussing Helen's current renewed interest in and engagement with her love of art, stated, "I think, had she got extra support at school, being able to make informed choices about her future and what she wanted to do, she wouldn't have gone to TAFE. Certainly not to do aged care." Unlike Anne, Helen's experience of a lack of student-focused transition planning resulted in negative impacts on her transition to post-school. Not being encouraged to follow her strengths and interests resulted in Helen choosing an employment option based entirely on "getting a job" rather than an employment option that would support her long-term engagement and wellbeing (see Chapter 5, Section 5.5 Helen). While the decision to focus on employment after school because this is what is expected as an adult is not unusual for young people on the autism spectrum (Goldfarb et al., 2021), in Helen's situation it resulted in a negative experience.

7.5.3. Student Development

The view that Helen shared regarding student development was very similar to that of Anne's. Helen summed this up with the comment, "It was pretty much just academics at school." She supported comments from Anne, stating that life skills class was "essentially just a free period": "That was about it. Life skills, nothing. We just sat in the classroom and did nothing at all. No worksheets, no actual lesson whatsoever. It wasn't anything to do with life skills." Furthermore, Helen stated, "I think the most in terms of life skills was maybe home economics, cooking, and how to mend clothes, make clothes, that sort of thing, but that's about it."

Again, as with Anne, Helen also experienced significant bullying during her senior years at school: "My last two years of high school were awful. They were really, really bad. In terms of bullying, really. That took a huge emotional and mental toll on me." She stated:

> It was from the people who I thought were my friends. It was someone I was quite close with, and then all of a sudden started hating me and treating me horribly. I felt quite alone because I didn't know who to turn to. When I did try to get help, they did nothing about it.

In terms of the impact that this had had on Helen, she shared that "I would have done better if I had been taught strategies at school to deal with academic and emotional difficulties. Had I had that help in school, I wouldn't have been as depressed. I don't know, I would have done better, I think, and been more okay with things." Helen described how the school did not offer any support or strategies to people like her who were experiencing social difficulties at school: "There was nothing really ever gone into or ever talked about. You had to learn about it on your own. Because of that lack of information, I guess, people like myself, people on the spectrum, don't know how to go about it." Helen described the impact that these social and emotional difficulties had on her overall wellbeing, as well as suggesting that it also impacted on her academic achievement. Ashburner et al. (Ashburner, Saggers, et al., 2019) found similar experiences and outcomes, with young autistic students who were experiencing bullying also struggling to manage their academic expectations at the same time.

7.5.4. Family Involvement

Helen's mother spoke very negatively about the level of family involvement that she had with Helen's schooling, sharing that "Poor Helen really missed out on a lot, I think, a lot of missed opportunities with the school" because of the limited communication that she had with them. "There was never any direct communication with Helen's teachers unless I went to the parent-teacher interview. And it was pretty much discouraged, emailing teachers directly." She went on to describe how "You could ring up and book an appointment or something like that but once again, if you're working and everything, you couldn't often get to appointments. It was really difficult to communicate with the school." Furthermore, Helen's mother described how this was very difficult because, "The girls didn't know how to ask for things that they needed at school. They didn't know who to go to and they would come home and talk to me about it … I would try and step in and help them and that sort of thing.” However, because of the difficulties with home-school communication, Helen’s mother often felt as if she were unable to help.

Despite these negative experiences with family involvement, Helen’s mother did admit that “Perhaps a lot of the lack of communication was possibly on my part. [With Helen], we were trying to deal with everything at home and there was just a whole heap of things going on.” She explained how, once the girls received their diagnoses, “I think having that external support gave me extra confidence in dealing with the school as well because I knew what I was talking about more than them [laughs], especially when it came to my child and what I felt that she needed.” Again, there was a distinct lack of evidence provided by Helen or her mother regarding the school undertaking any role in training or empowering Helen’s family to collaborate and be involved in transition planning options (see also Beamish et al., 2012). Rather, Helen’s family learned how to do this themselves through the experience of communicating with schools regarding their daughters. For Helen, however, this experience was not gained at a time that positively supported her transition-focused planning.

7.5.5. Program Structures

Helen’s perception regarding program structures focused on the lack of flexibility of the school’s program and on its limited resources. Her descriptions throughout the interviews related to “really limited classes” with a “very limited art program”. More importantly, Helen felt that there was “always a set curriculum” and “There’s always a set amount of kids in every single class, even if it was a class they didn’t flourish in. They couldn’t really change it without signing several forms and talking to the Vice Principal [emphasis] about it and that sort of thing.” Furthermore, Helen was adamant that there was “no taking into consideration the students that behaved differently, thought differently”, and she felt that there was “a lack of encouragement as well, especially for kids that had a real passion for something.” To Helen, the school purpose was, “Get us through school and kick us out.” She explained how, “Even in other classes that I was doing, [I was] sketching on the sides of pages because that’s what kept my interest going throughout the class”, but she stated, “It was English and English, not English and Art.” So, while she used art to maintain her level of alertness throughout classes, this strength was never incorporated into what she was studying.

The impact of these inflexible program and resourcing structures, coupled with limited student-focused planning and family engagement, resulted in Helen choosing “the simplest option for herself at the time”. Instead of following her strengths and interests, and investigating her post-school options with art, Helen focused on “getting a job”. In the end, the lack of compatibility between Helen and the job resulted in her experiencing poor wellbeing during the key transition period after school. Fortunately for Helen, strong family support had encouraged her to focus on her wellbeing through following her strengths and interests. For many young people with autism, engaging in their strengths and interests allows them to experience a sense of autonomy, competence, and relatedness with a likeminded community (Grove et al., 2018). Thus, for Helen, a more flexible approach to school program structures that allowed her to follow her strengths and interests as she transitioned to post-school options may have resulted in a more positive QoL during these initial years of transition.

7.5.6. Interagency Collaboration

In relation to interagency collaboration, Helen’s mother was adamant that “That didn’t happen for Helen. That outside support wasn’t integrated into what happened at school.” While Helen also attended a private psychologist, the report provided was never even referred to by the school, let along integrated into the strategies that were used to support her. Additionally, Helen’s mother expressed her frustration that Helen had “Never been offered an OT [Occupational Therapist]” through the schooling system and never received any kind of therapy support at all. Given the positive impact that access to these resources had had on Helen’s life post-school, Helen and her mother felt that it could have made a positive difference to her experience of school.

7.6. Frank

7.6.1. Introduction

It had been more than 15 years since Frank completed secondary school at a medium sized regional city state school. Despite the number of years since completing school, Frank still responded with a great deal of emotion as he spoke about his school experience: “Hated it [school]!” Frank shared his belief that school did little to prepare him for life after school: “Now that I’ve finished school, for many years, I didn’t know how to do anything, to tell the truth”, and that most of what he had learned was from negative experiences since school: “I’ve learned from the school of hard knocks.” Frank’s mother agreed with this perception. When asked what Frank learned at school to help to prepare him for life post-school, she stated, “Nothing.”

7.6.2. Student-focused Planning

SET plans were introduced into Queensland schools in 2006; thus, when Frank completed Year 10 and moved to senior schooling, SET plans were not developed. At this time Individual Education Plans (IEPs) were mandated for students with significant disabilities; however, they were optional for any other students with disabilities in Queensland State Schools (Queensland Government, 2019). Neither Frank nor his mother mentioned the development of a specific transition plan for Frank. Given the time at which Frank completed Year 10, this was most likely a result of limited policies requiring or supporting the development of such plans at that time.

Despite this, Frank expressed a very clear idea of what he would have liked to have done, stating that “I would have like to have learned a trade, or, even then, I would have loved to go to university.” However, Frank felt that,

> Because I had a disability. I was in the SEU [special education unit]. We were not taught to get a trade or learn things. We were taught simple very things that will help us to be on a pension and that would be the end of us. We’re teaching a little bit of this, a little bit of that, but we really couldn’t care about you.

Frank's mother also felt that there was little, to no, preparation for post-school life, let alone a transition plan that the young people, or their family, were part of developing: "You find that they go through school, and people don't think of what's going to happen after school. There's no planning." Furthermore, Frank's mother suggested that Frank was not given the option of being a part of the decisions regarding his education plans, and that, even if he had been, Frank "Would have just said 'Yes, yes, yes' to everything." She felt strongly that he would not have had the skills to be an active contributor to his transition plan, and there were no strategies implemented to help young people to be able to contribute to these decisions at the time that Frank was attending school. This lack of student-focused planning resulted in a situation where Frank completed his schooling with no clear plan of what was to come after school.

7.6.3. Student Development

From Frank's perspective, he believed that "I didn't learn much, anything much in there [at school]", and that "My teachers were planning to set me up to work at Endeavour [a local disability employment provider] and that'd be the end of my life. Not going out and getting a trade or a Certificate III." Frank did, however, mention that "I was always acing class because I had the most capabilities", but they "taught us how to make sandwiches pretty much." Frank's mother supported these statements throughout her interview. She felt that all around, Frank was given very few opportunities to learn new skills at school. She described his academic skills after finishing school as "Poor. He did get through to Grade 12, but he's probably – Grade 3/Grade 4 is probably his level." Frank's stepfather added to this that, "He can't type and he's not very good at writing; that's probably from his school days." They also indicated that there were no employment skills taught at the school, and the life skills taught were "Very little. In those days, it was just the beginning of it." Instead, his mother believed that they should have been learning "practical life skills" and be working towards "qualifications".

Most importantly, however, Frank's parents believed that he needed to be taught social skills, including dating and sex education, and strategies to manage his emotions. When asked if these skills were addressed, Frank's mother's response was, "No, never. Nothing [like this] was ever addressed at school." Frank's stepfather added, “They think it’ll never happen you see.” Frank’s mother did admit that “Frank’s learned more out of school than in school. He will tell you that as well. He needed that maturity to take on stuff. He just couldn’t grasp things.” However, she still shared that the development of life, social, and emotional skills needed to start being addressed at school because it took some young people so long to learn them.

7.6.4. Family Involvement

Frank’s mother stated that “There was nothing really planned for the future, I found back then with education”, so “I planned it [the transition to post-school].” She went on to clarify that, “Because I was in the Education Department, I knew about the post-school options.” When asked if she tried to work with the school around this transition plan, Frank’s mother responded, “Because I worked at the school, yes”, but “The communication was so poor …” As with most participants, Frank’s family took a leading role in the transition planning for his transition to post-school. Although this planning occurred separately to what the school was doing. This lack of family communication and involvement appeared to be quite ineffective from a transition planning approach. There was no knowledge, from the family’s perspective, as to what the school was doing, and a similar lack of knowledge, from the school’s perspective, as to what the family was doing. Goldman and Burke (2019) suggested that a critical factor in successful transition planning is where all stakeholders – schools, families, agencies, and organisations – are working together to support autistic adolescents as they transition to post-school options.

7.6.5. Program Structures

Two key points within the topic of program structures were discussed by Frank and his parents. These were exclusion practices, and the social difficulties that these practices caused. While both practices were discussed in terms of the impact that they had on school climate, there is a clear connection with other aspects of program structures within transition planning – program characteristics, program evaluation, strategic planning, policies and procedures, and resource development and allocation – as school climate is most often a reflection of these decisions (Kohler & Field, 2003).

Frank's mother shared that, "Originally, he had a lot of friends." She went on to explain that "It was exclusion. That's the thing. 'You're in [the] special ed unit now that your mother has brought this to the surface.' Because I said, 'I think this is what it is.' They said, 'Right, that's it, off to the unit'." Furthermore, "They put him into the special education unit, and he wasn't allowed to play with his mate, and that really killed him. So, the socialisation was totally cut off." Additionally, Frank's mother described how there were no other students in the special education unit at the time who had positive social skills to be a role model for Frank. Although the school did try to implement strategies for Frank to go into the mainstream environment, Frank's mother described how, "That wasn't real great … see he gets bullied and that's what happened. You went out, you'd get bashed. Well, he did." She felt that the school culture was such that, "Once you're tagged in the unit, you're a special needs child. That's it. You had a stigma." Frank supported his mother's statements with one simple, but important, statement: "I found it almost impossible to make friends [at school]."

These difficulties with social skills and with developing and maintaining friendships continued from school through to post-school for Frank. Throughout the discussion about his QoL, both Frank and his mother described the difficulties that Frank experienced with friends and intimate relationships as an adult. Cheak-Zamora (2019) found a strong connection between the friendships developed throughout school and the experience of friendships and relationships as an adult. For Frank, the poor school climate and his exclusion at school appeared to have contributed to his social difficulties as an adult.

7.6.6. Interagency Collaboration

Regarding interagency collaboration, both Frank and his mother emphasised their disappointment that, at the time, Frank was not able to use his final years of school to gain TAFE qualifications that may have assisted in his search for employment. Frank repeatedly commented throughout his discussion about school that, "I would have liked to have learned a trade", and "I could have got a certificate." Frank's mother, however, shared that "They didn't have a lot going back then. It's all come in now, which is fantastic, especially because they can get their Certificate I or Certificate II's all the way through school. That never happened, we never had that opportunity." As a result, Frank had gone back to TAFE and had completed his Certificate II in Aged Care many years after completing school. From this, both Frank and his mother were hoping that he would finally gain employment.

7.7. Paul

7.7.1. Introduction

Paul attended a small regional state secondary school over 20 years ago and had lived in the same small regional town since completing school. Paul did not have a lot of information to share about his time at school, except to focus on the things that he had learned that had helped him as an adult. He admitted that he "learned a little bit" of the skills and knowledge that he needed for post-school life at school, and a "little bit more" after he had completed school.

7.7.2. Student-focused Planning

Regarding student-focused planning, Paul stated, "In Grade – I think in Grade 10 – we were allowed to choose our own subjects." When Paul attended secondary school the SET plan was not used to guide students' choice of subjects or to plan their transition to post-school options. As Paul attended the same school in the same year as Bruce, and given the comments provided by Bruce's mother who worked at the school, it is likely that Paul would have had an Individual Education Plan (IEP) in place throughout his secondary schooling. Paul was unable to remember the details of this plan and whether it had been focused on his personal goals, strengths, and interests, or not. He did, however, share that the school did not help him work towards his goal of working in the climatology/meteorology industry.

Throughout school, Paul was clear that his main interest, the weather, was not addressed except for doing a unit on weather in multistrand science. For Paul, this was obviously a time when he experienced high levels of competence. He commented, "I did multistrand science, which, in the weather … when we did weather, all of the other kids said, 'What the heck!'", indicating that they had been surprised at his level of knowledge of this topic. During this discussion, Paul had a large smile on his face, showing the pride that he had felt with this acknowledgement.

7.7.3. Student Development

Most of Paul's discussion about school related to the skills that he did or did not learn during school that had helped him in his post-school life. Paul stated that the most useful skill that he learned at school was "Learning how to cook." He described how "We'd go into the unit [special education unit] and then we'd go up to the home ec [onomics] room and learn how that works and learned how to cook food". "We learned how to cook those basic meals. Nothing too fancy, but just like a real basic necessity of life." As part of learning how to cook, Paul also shared that "In our school we used to go out shopping." Thus, learning how to shop for, and cook, basic, healthy meals was something that Paul felt had been extremely helpful for him as an adult.

Another area that Paul did discuss was the social relationships that he had at school. Paul found that "It was a little bit difficult to have friends sometimes at school. I used to get picked on a little bit as well" although he admitted that "It was more so in primary school than high school": "You know, everybody was more sort of grown-up, and they'd learned a bit more too in high school." When I asked Paul if the school had helped him to deal with the bullying that he had experienced, he replied, "I just got told to walk away or to ignore it." He also stated that there was no support, and he was not taught any strategies, to deal with the anxiety that he experienced during school. Thus, Paul had developed strategies as an adult to deal with his anxiety.

Paul did comment that one area where he would have liked to learn more was with budgeting. He stated, "I probably would have liked to have learned how to budget a bit better." Paul admitted that at first "It started off a bit funny … but now … it makes it pretty good." Given the significant correlation between financial wellbeing and material and physical wellbeing, this could be considered a key area for supporting young adults as they transition to post-school options. Furthermore, the need for greater skill development and support for budgeting was mentioned by every participant in this research study (see also Cheak-Zamora, Teti, Peters, et al., 2017).

7.7.4. Family Involvement

Paul shared that his father was involved with his schooling during primary school, but “not so much” during secondary school. Paul was, however, one of the three students on the autism spectrum who started secondary school in the same year as Bruce. Thus, although Paul’s father was not significantly involved in his transition to secondary school, Paul was supported by the members of the local autism support group who worked with the school to support all three students (see Section 6.10 Bruce). Thus, throughout school Paul relied on the school staff to meet his needs.

7.7.5. Program Structures

Paul did not speak about the program structures of school while he attended school, except to talk about his participation in the special education unit (SEU). From Paul’s perspective, this was a positive experience that taught some of the important life skills that he needed in his transition to post-school. These skills related specifically to shopping and cooking for himself, but, to Paul, these were very important.

7.7.6. Interagency Collaboration

Interagency collaboration was not spoken about in Paul’s interview. Although he did describe how he completed a Certificate III and IV in Information Technology through the local TAFE because he “likes to tinker with computers”, and because this helped him to set up and manage the local social media weather group, this occurred after school.

7.8. Tamara

7.8.1. Introduction

Tamara attended a small regional P-12 Christian school, attending the same school throughout her schooling. At the time of the interview, Tamara had recently graduated from secondary school, approximately 18 months prior, and was in the early stages of transition to post-school. Tamara admitted that “It wasn’t a good experience for me in the school. I hated high school the whole way through.” However, she also stated that “I got my QCE, so … I’m very happy about that. I actually … when I got that in the mail, I actually jumped up and down in excitement. I was really happy.”

7.8.2. Student-focused Planning

Tamara and her mother both stated that they did not remember engaging in the SET planning process, although Tamara’s mother did state that “She had an IEP [Individual Education Plan] in place”, and that this was the main way that Tamara’s needs were met throughout school. Tamara also felt that “We had a plan set out for me”, and that she worked closely with the special education staff members to develop that plan and to ensure that she was working towards what she wanted to achieve in her transition to post-school. Both Tamara and her mother spoke about her goals to work in childcare and how this was incorporated into her IEP. Her mother stated, “She did work experience [in childcare] first, I think in Grade 10, through the school. The director said that this is what you are meant to be doing and that was really encouraging for her.” Tamara’s mother described her sense of relief, “Ah, good, so she has found her little niche and she can be good at that.” From that point, Tamara’s school plans were designed to help her to move towards achieving her goal of working in childcare, and she was offered a school-based traineeship in early learning in Year 12: “She was doing that through the school because they have an early learning centre there as part of the Christian school.” Tamara continued through to the completion of the traineeship; however, she was disappointed that her employment did not continue once the traineeship was finished.

Throughout the interview, Tamara spoke repeatedly about how much she enjoyed childcare and that she felt that this was the industry in which she wanted to continue to work: “I see my job, like … childcare is something that I want to work long term. It’s something that I’m passionate about.” Tamara’s mother supported this, saying “It was mainly her decision what she did. That’s really what she wanted to do, and she’s quite happy with it.” From Tamara and her mother’s perspective, the school were very supportive of Tamara’s choice and actively worked at supporting this.

7.8.3. Student Development

Tamara shared a positive view of the life skills that were a part of her secondary education. She stated, “I did actually learn those skills at school”, discussing skills such as budgeting and managing money: “We actually learned life skills like phone calls and things like that”, and “We did work plans and organising steps into how to make a meal.” Tamara stated that it was “In Grades 11 and 12, and [a little bit] in 10 and 9, I think, that was the year where they really took off with helping students with those life skills”, indicating that the school saw the teaching of life skills as a key aspect of the students’ secondary school education. Furthermore, Tamara described how many of these skills were included in the subjects that she was studying, such as “Doing English communication, learning about rental agreements and things like that”, further indicating that these skills were offered to all students as part of an inclusive education program. On top of regular subjects, Tamara also stated that “I did vocational studies and a Certificate I in business.” Overall, Tamara saw her secondary school experience as one that addressed life skills as a core part of the school curriculum. Furthermore, she stated, “I think they did” when asked if she thought that these life skills learned at school had helped her in her transition to post-school. She certainly believed that the school-based traineeship in early learning, and additional employment skills, benefited her in terms of her capacity to find and succeed in her chosen career path. She commented that, “While learning about work signs might not benefit somebody like her [her sister], who had a job back then, it really did benefit me”. Tamara felt that “Even if I did have some knowledge”, learning about these life and employment skills “deepens your understanding”.

One aspect of education that Tamara felt was not as positive was the support for, and teaching of, social and emotional skills. Tamara stated that making friends at school “was kind of wobbly” and described how “In high school I had nothing but emotions.” She felt that, although “they worked on it [social skills] a little bit”, she wished that there had been a greater level of support and strategies taught at school for dealing with challenging emotional situations: “The social aspect of school is so complicated … especially now as you’re going through adolescence. I was friends with everyone below me or above me, but not in my year level.” Furthermore, Tamara stated, “I definitely felt very misunderstood by my classmates, and they weren’t a very nice group of people.” Tamara’s mother supported this experience saying that “She struggled a lot with friends; none of the girls really wanted to be her friend. I would like to have done something to help her with social skills”, although her mother did suggest: “She didn't have a great problem with bullying”, and that the school actively worked to address any bullying that did occur.

Tamara did speak very positively about one aspect of the school’s attempt to address social and emotional learning in the program: “We did have SCG, which was strength and character groups”, stating, “It’s really helpful just to have those social things.” Tamara described how SCG was a program that was “more about understanding each other and ourselves”, and that it provided the students with a common language to talk about some of the problems that they had, and that “There was a community where we were reminding each other, ‘Hey, remember what we learned in SCG?’.” Tamara stated that, “The more understanding the school did push out, the better that that environment was. I think it’s interesting how these little things, especially SCG, did impact [on] it [school culture].” Simultaneously, Tamara also described how many students did not enjoy or see the value in these groups: “My class, pretty much everyone was against it [SCG], I don’t know why. It makes me really sad that attitude they had towards those kinds of things, especially SCG.” As a result, the program was stopped: “They actually dropped SCG and all that, and I noticed the culture was slipping.” Tamara was very clear in stating, “I wished that school is based on communication and social skills more than it is [on] science and history.”

7.8.4. Family Involvement

Tamara’s mother described limited family involvement with Tamara’s school program; however, she spoke about the key role of the family as she transitioned from school to post-school, and the limited support provided to the family during this time. When Tamara was at school, Tamara's mother admitted that "If she had any issues, she would go to the learning support teacher." Furthermore, she described how:

> I did go over stuff with the learning support teacher, and she was a quite helpful. She [Tamara] would talk to her, or if she had something that upset her, or she had to leave the classroom for whatever reason, she could go and talk to her. If I had an issue, I would ring her and say, 'Can you fix this for me?' I didn't have to go through other channels.

Tamara's mother stated that, "We couldn't have made it through school, I don't think, without her" (see also Goldman & Burke, 2019).

However, Tamara's mother did still feel that "As far as the future goes, I think they're not really doing anything now or never really put anything into place. It's like, 'Well, this is your thing that you're doing. Then, see you later', basically." From her perspective, although Tamara was offered the school-based traineeship, it was still the case that everything "just ended" once she had completed Year 12. She stated that "I just think, as a family, we haven't had support because we have struggled a lot [with the transition]." This would seem to have been exacerbated because Tamara and her family lived in a regional country town and there were limited resources to support people, particularly adults, who experience disability within that community. Thus, now that Tamara had finished her school-based traineeship and her employment had ended, the support for Tamara moving forward had become primarily the responsibility of her family and herself. This is a common experience for families of people on the autism spectrum living in regional communities in Australia. Even if young adults are eligible for formal supports such as disability specific employment agencies, supports for continued personal development, or community access, there are limited organisations that provide these supports within regional areas (Johnson et al., 2020).

7.8.5. Program Structures

The program structure of the school was described by Tamara as actively evolving over the time that she was there. She stated that, in "Grade 7 and 8, I pretty much felt … I was thrown in the sea pretty much. It felt like they were expecting me to swim when I didn't know how, kind of thing." However, "In Grade 7, they officially realised, 'We've got quite a few people who need help; let's do something about it.' So, I did get help in Grade 7 towards the end." Tamara went on to describe how, "When I hit Grade 9 and 10, I was very supported"; "They were really working hard towards getting us that help." Tamara's mother also spoke positively about the work that the school did to improve the experience for Tamara and other students with disability in the school, stating, "They're getting a reputation for having a good special needs unit."

From Tamara's perspective, it was her teachers who had the greatest impact on her success at school: "It's the people that make the difference. I think teachers do have a big impact on the child's life", although she admitted that "There were teachers who just didn't get me so would put me in the too hard box. I mean, you get that; not all schools are perfect." Overall, however, "The teachers were very passionate about wanting the kids to succeed, especially in Grades 9 to 12." Tamara felt that "The teachers at first when I started high school didn't understand", but she stated, "Our teachers were very fortunate and actually got training in how to deal with children like me." Furthermore, Tamara spoke very highly about "Teachers who actually want their students to succeed and actually go out and learn how to deal with that." This understanding of autism featured heavily in Tamara's descriptions of those teachers who helped her: "The subjects that I did well in had really good teachers" (see also Hummerstone & Parsons, 2021). Tamara spoke very positively about the learning support teacher: "Not only was she really passionate about getting Grade 12s into a solid position when they got out, but she was also very … like she understood. I think she understood me better than the other teachers did." Tamara indicated that

> She's got ASD grandchildren, and her son is ASD, and so she had a real passion for people like us and getting us somewhere, and she understood the social aspect. She helped me a lot. She was a teacher who was really willing to help me, and she was really good.

Throughout the interview, Tamara spoke positively about the enrichment room, which was what the special education program was called at her school. She described how “I could go to the enrichment room whenever I was feeling stressed”, and that “I would sit down in my spare [lesson] with the enrichment staff, the teacher or the teacher’s aide, and we would break it [assignments] down. That really helped.” Tamara felt that “We had that within the enrichment room where we were like a really knit … like [a] community of people who understood each other. I did get a lot of advice from the enrichment people.” Tamara’s mother also referred often to the learning support teacher who ran the enrichment room and acknowledged that “She also did help probably a little bit with Tamara’s studies as well and helped her be organised through [Years] 11 and 12 and probably before that as well.” Specifically, while Tamara spoke positively about having access to the enrichment room and the support that that staff provided to her, she did not feel the same level of positivity towards being segregated from her normal classes for specific support. She described how “I actually got taken out of geography and graphics to get help with my subjects and things like that” but felt “It was annoying because we were already struggling [in these classes]. I just didn’t like the fact that I had to leave class at all.” Tamara’s perception that support provided by the school was helpful, but that the support should not be forced on to students in a structured way, aligned with the findings of Humphrey and Lewis (2008). Young people on the autism spectrum acknowledged that they required additional supports to succeed at school; however, they did not want to be segregated and separated from their typical classes and classmates to receive this support. Rather, they suggested how supports were provided was key to including all students effectively (Autism Spectrum Australia [ASPECT], 2013; Humphrey & Lewis, 2008).

Despite the significant levels of support provided to Tamara throughout her secondary schooling, she did still find that she struggled with the “crammed curriculum”. Tamara stated, “I hate how crammed school was. I just don’t like the way it’s set up. I hated the fact that we had to cram so much in.” She described how “I find it really easy to do one task at a time and then move on, but you can’t do that in school; you have to jump between. You’ll have homework from different subjects and then the teacher will be like, ‘Why didn’t you do this, this, and this?’” and “You’re like, ‘I’m trying to focus on four different subjects here’.” Additionally, Tamara described how she struggled to complete homework: “I found that after school the mental exhaustion from socially [interacting], and learning and all that, I really struggled having to do more at home.” Tamara’s mother also mentioned this difficulty, stating that “I learnt that I’m not going to stress myself out about it [homework], because I just get too upset and I’m not going to deal with the stress of helping her. Anything that had to done at home, I hated because it was just so stressful.” Both Tamara and her mother described how, by the time that Tamara got home from school, she was tired, and they would end up arguing about homework every day.

7.8.6. Interagency Collaboration

The interagency collaboration described by Tamara and her mother was very similar to their experience of family involvement. Although the school did collaborate to ensure that Tamara was given the opportunity to complete her school-based traineeship, now that school and the traineeship had finished, so had the collaboration and the support provided through this: “She finished up her traineeship and, once her contract was up, they didn’t keep her employed. They said, ‘Okay, we don’t have a place for you anymore.’ Now she's looking for work.” The process of looking for work, for Tamara, had become something that she had to do herself with only family support. Furthermore, while Tamara indicated that she would like to continue studying early childhood education, the support that she received to complete her school-based traineeship may not be offered again. Tamara’s mother stated that “She got extra support through the Cath Dickson system. Because she has Aspergers, she got extra help because the study involved in childcare is not easy.” However, when asked if this help would be provided if Tamara wanted to continue studying, she replied, “I don’t know.”

7.9. Eric

7.9.1. Introduction

Eric was home schooled until the end of Year 8 and was then enrolled in a regional Christian school to complete Year 9 through to Year 12. Eric was described by his mother as “a very high achieving student at school”, and Eric himself stated that “I’ve always loved learning. I liked the classes. I liked the learning”, although he did admit that initially he found the social aspect of attending school difficult. Despite the social difficulties experienced by Eric in the early stages of secondary school, in his senior years Eric stated that he was “a prefect in my school”, and Eric’s mother described a saying that staff and students used at Eric’s school: “Don’t Google it; just ask Eric”, indicating that Eric’s intelligence and memory were highly regarded during his school years. Eric graduated from school four years prior to the interview, and, while he indicated that he looked back on his time in secondary school with fond memories, he admitted that “I don’t want to go back.”

7.9.2. Student-focused Planning

Student-focused planning was not an area of transition planning that was identified as important by Eric or his mother, although both admitted that this most likely because “Eric knew what he was going to do.” Eric’s mother described how

> In terms of preparation for transitioning, they did have a person. I don’t know her role, but she talked with the students about what they would do after school. So, I did see her working with some students, but Eric just knew what he wanted. They knew he had the grades to apply. So, it was almost like they didn’t need to work with him.

In terms of working through the SET plan, Eric’s mother recalled: “I don’t remember that with Eric [receiving the paperwork]. It’s not to say that it didn’t happen though.” She went on to state, “I do remember a night where they invited us as parents along to talk through that stuff, but I didn’t go.” Eric’s mother admitted that

> I did probably switch off a little bit to that because Eric knew what he was doing and that was that. Because he’d been to the National Youth Science Forum, they were already told if you’ve got the marks that you thought you were going to get, then they were going to accept you.

Thus, from Eric’s mother’s perspective, “The focus was really on getting them to apply through QTAC [Queensland Tertiary Admissions Centre], and then get the best grade you can so that you can get the course you want.”

Thus, high academic ability appeared to be s protective factor for Eric in the area of student-focused planning. As a result of Eric’s exemplary academic record and interest in science, he was given the opportunity to attend the National Youth Science Forum at the Australian National University (ANU) at the beginning of his senior year, thus providing a high level of certainty with regard to his acceptance into his degree of choice at his university of choice. Eric's strengths and interests were closely aligned to the academic focus of the school and to enrolment in tertiary studies; therefore, his strengths and interests were easily supported and encouraged within the schooling system. As a result, the alignment of educational and post-school goals was easy to achieve for Eric, his family, and the school.

7.9.3. Student Development

Despite his high level of academic success and his focus on achieving high academic outcomes, Eric also described areas where he experienced difficulties during his secondary schooling. Eric stated that, although "I liked the classes, I liked the learning", "I had no friends in Year 9." He went on to recall how he "Got to Year 9 and very quickly realised … how lonely it is during lunch breaks, when you are sitting by yourself, and you have to somehow pass the 40 minutes until the next class." Eric described this as a "difficult time". Fortunately, Eric used his strengths in learning to address these difficulties. He stated, "I kind of had to figure it out. It took me a good year or so, but I started to make friends." He described how he was able to take his knowledge of public speaking and to use the strategies from this knowledge to learn how to communicate with his peers and to start making friends: "I was able to take this one thing that I'd done and kind of use it to … use it in another area. It was very much a case of learning on the spot and kind of taking the mistakes as I saw them and iterate, iterate, iterate." Although Eric acknowledged that this strategy did work, he was quick to add that "I don't think I quite fit in at that point either. I look back at some of the interactions that I had. I wasn't quite at the stage that people would've considered normal yet." More importantly, Eric emphasised that, in terms of developing social skills or life skills, "I didn't get any of that from school. I got all of that from home … It wasn't something explicitly handled [at school]."

Eric's mother supported this viewpoint when she stated, "My perspective is that no, I didn't see those things being addressed. I just saw a really strong focus on academic results at that school." Furthermore, she shared her concern that "He could have been maybe bullied and targeted because he was a high achieving student. But he was in such a lovely group of students and such beautiful nurturing teachers that they celebrated kids with differences, I guess." Thus, although Eric did not experience any serious negative outcomes from his initial social difficulties, this resulted from Eric's willingness and ability to develop strategies for himself and because he was attending a school with a strong sense of school connectedness, rather than through the explicit teaching or development of social skills or life skills at the school. Additionally, Eric's mother shared that "I didn't see a focus on preparing for wider life skills", but "As a parent, I'm very happy to do that [teach life skills]. I see that as part of my role as a parent." Importantly, she stated, "I don't know if the school had [taught life skills] that it would have made much difference."

Similarly, Eric described the difficulties of navigating social relationships, sexuality, and expectations as an adolescent and the lack of support provided by the school in these areas as "very damaging". He described how "I didn't understand any of what I was feeling at that point", and that "I just tried to pretend like it didn't exist." As a result, when discussing emotional wellbeing and whether this was addressed at school, Eric acknowledged that "School made it worse". Given the significant levels of anxiety that Eric still experienced as an adult, this would again seem to be a key area that could be addressed by schools (see also Cheak-Zamora et al., 2019).

7.9.4. Family Involvement

Eric's mother, having home schooled Eric until the end of Year 8, had been a highly involved and knowledgeable parent regarding Eric's education. Despite this, Eric's mother indicated a very limited amount of involvement in Eric's final years of schooling, although she admitted that "My role as a parent was so much easier because I just switched off because he knew what he was doing." Additionally, she acknowledged that "I did take a step back because I didn't want to be one of those hyper-involved parents that did the thinking and the navigating for them. I wanted them to be responsible for that journey." Regardless, Eric's mother did state that, "I saw nothing from the school" and that "A lot of the school's communication with parents was actually through Facebook and using that as a means of communication for me was ineffective." Although Eric's mother described very limited involvement in Eric's final years of schooling, her involvement in his transition to post-school –

attending university, organising living arrangements, acting as an emotional support person – was, and still is, extremely high.

7.9.5. Program Structures

Both Eric and his mother spoke positively about the school structure and characteristics, and both believe this had a positive impact on Eric's time at school and transition to post-school. Eric's mother stated that

> The school did an amazing job of making every student feel nurtured and supported. It was a smaller school. So that really helped. And the teachers and their relationship with the students … In Year 12, I saw that particular year level just afford such agency to the students and they really gave them a lot of responsibility. In terms of nurturing and trusting the students and treating them as agentic adults, I thought was excellent.

Eric also spoke about this when he commented that the "School treated us sort of like miniature adults. And that was really great, the responsibilities that you got. I was a prefect in my school. And we met once a week and actually organised stuff and ran things and that was really, really good." Together, these comments suggested that the school staff fostered a sense of school connectedness for all students and actively encouraged the students to take responsibility for their learning and the development of a positive school culture. Shogren et al. (2016) suggested that providing for active engagement and responsibility in the senior years of schooling supported the development of valuable skills that can be used in post-school options. For Eric, a high achieving student who was focused on academic achievement, the typical academic school structure coupled with a positive school culture resulted in an overall positive school experience.

7.9.6. Interagency Collaboration

Neither Eric, nor his mother, spoke about interagency collaboration between the school and other organisations such as the university that Eric attended. Given that Eric was such a high achieving student, and that he had not received any additional supports while attending school, this experience of interagency collaboration would fit within the experience of most students who transition from school to university. That is, the expectation is that students who successfully complete school have the skill level and opportunity to manage their own school to post-school transition.

7.10. Bruce

7.10.1. Introduction

Bruce attended the same small regional state secondary school as Paul, and at the same time, completing secondary school over 20 years ago. Like Paul, Bruce had little to say about his secondary schooling experience except to say, “School was okay, [but also] it was painful. I just wanted to get out.” Bruce’s mother, however, had a great deal to share about Bruce’s experience at school, her experience as the mother of a student on the autism spectrum, and her experience as a special education teacher aide who worked at the school. Bruce’s mother commenced working at the school shortly after Bruce started attending the school and continued to work as a teacher aide for many years after Bruce graduated. As well as sharing her personal experiences, she shared her perception about the school’s approach to supporting students on the autism spectrum, and students with disabilities in general. Furthermore, she commented on how much this had changed over the last 20 years.

7.10.2. Student-focused Planning

As with the older autistic adults who participated in the research, Bruce attended school prior to the introduction of the SET plan. Instead, throughout secondary school, Bruce’s mother confirmed that “we had an IEP” to determine Bruce’s needs and what would be done to support him throughout school. Although Bruce’s mother indicated that it was too long ago to remember the details of the IEP, she spoke openly about the approach taken at that time to support students to follow their areas of strength and interest: “Whatever the kids wanted to do, we would try to support them.” An example provided by Bruce’s mother as to how the school would try to cater to individual students’ strengths and needs was how “The TAFE would come and say, ‘Kids, what do you see yourself doing?’ So, then they’d write down what they’re interested in, and then the TAFE would say, ‘Well, we could offer you this, this, or this’.” From Bruce’s mother’s perspective, this was an effective way of ensuring, particularly in senior secondary years, that the students were following their interests.

Despite this, when Bruce was asked directly if the school supported him to follow his interest in the aviation industry he replied, “No, not really”, although his mother did describe how Bruce had completed his work experience at a local aviation company and the positive experience that this had been for Bruce. She stated, “The owner of the aviation company was wonderful to Bruce. Bruce worked out there for a long time after that [work experience] had finished.” Furthermore, Bruce’s mother explained that “They were really good at the school, really good. They would allow him to go out of school for the day and go and work at the aviation company because he loved it so much.” Thus, while it may not have been possible for the school to respond directly to Bruce’s strengths and interests in aviation, there were areas throughout his schooling where this was supported. This ability to provide and support direct work experience in the industry in which a student is interested, is a positive example of incorporating individual students’ strengths and interests into their schooling, and it is considered best practice in terms of transition-focused education (Kohler & Field, 2003).

7.10.3. Student Development

Bruce’s mother shared very little of what Bruce and his cohort learned while at school except to say that “He went right through to the end of Year 12”, and “He went through because he wanted to, because he really wanted to get into aeroplane stuff.” From her perspective, she was happy with the outcomes of Bruce’s schooling, stating that “He came out quite good”, and that “He was lucky in as much as he had really good teachers.” Bruce shared his mother’s perspective, also stating that “The teachers were pretty good.”

In terms of skills taught, Bruce’s mother did describe a program that included a variety of life skills such as shopping, cooking, helping students to get their driver’s licence, employment skills such as work experience, and working closely with TAFE to provide certificate qualifications. She also talked about implementing programs to support the students’ social and emotional skills: “We did a lot of social skills stuff”, including the use of social stories. Bruce’s mother described the importance not only of teaching social skills, but also of the social friendships that Bruce had while in secondary school. She described one of Bruce’s closet friends at school and how they became friends, indicating that “They’ve been friends ever since.” She talked about the importance of Bruce’s having good friendships during school and how Bruce’s friends were like part of the family: “They’d come out to the farm and stay all the time. Go on holidays with us. It was really good.” Bruce’s mother saw his positive friendships at school as a protective factor for Bruce’s wellbeing, and acknowledged the positive outcomes, such as his current job, that had come from those school friendships well into his adulthood (Ryan & Deci, 2017).

7.10.4. Family Involvement

Bruce’s mother described high levels of family involvement with the school and Bruce’s education. Bruce’s mother was already significantly involved with the local autism support group when Bruce was transitioning to secondary school. She shared how “There was about three families who had kids going into the high school, and we rang the principal and said to him, ‘We’ve got three ASD kids coming to your school. We’d like you to come and see us at the ASD support group’ … ‘Tell us what you’re going to do for our kids?’” Bruce’s mother went on to describe how it took several invitations before the school principal did meet the parents, and that his first response was, “We’ve never had autistic kids before.” Fortunately, the three families stayed in close contact with the school staff and a close working relationship was formed: “They asked me to come in and have a chat to all the teachers before he started. Then I started working there; that was probably a good benefit for everybody” because “If anything happened, they knew they could talk to me about it.” Bruce’s mother also described the benefit of her working at the school for Bruce. She explained that “We did have some incidents at school, so I said to him, ‘If anything happens, you must come and tell me’.” Thus, not only did the school staff have easy access to talk to Bruce’s mother and a close working relationship with her, but also Bruce had the advantage of having someone who knew him well and was available to talk to him at school. This close working relationship continued for Bruce’s mother long after Bruce graduated from secondary school, and she stated that, “They, the school staff, still ask me how Bruce is going.”

7.10.5. Program Structures

The program structures used to support Bruce and the other students with disability in his cohort were described by Bruce's mother as being in the beginning stages when Bruce was at school. From her perspective, this had both positive and negative outcomes for the staff, students, and families. The positive aspect of the early development of the special education program was the level of flexibility that was provided to the staff and students. She stated, "I worked at the high school, and we had a very good unit at the high school at the time. We used to do a lot of support there." Furthermore, Bruce's mother described how "We would work it so that they could get whatever it was they needed." While the students "had separate math classes, separate English classes, everything else was mainstream", and the special education unit worked to provide the students with as many life skills as possible. This included providing qualifications through TAFE, obtaining their driver's licences, and developing shopping and cooking skills to support post-school life.

Bruce's mother saw this freedom to work on what was important to the students and their families as an advantage, and she believed that this had changed in more recent years: "They're restricting their subjects now so it's all towards academia. The government says to schools or to teachers, 'You've got to teach this, this, this this, and this, this and this'." From her perspective, the overcrowded curriculum had reduced the opportunities for students to learn the various life skills that they need when they transition from school to adult life: "I think there needs to be not so much push to try to get these kids through Year 12 academically. Instead, get them out working. Get them out doing something meaningful." This reference to the importance of learning life and employment skills was strongly supported by Pillay and Brownlow (2017), who found that the strongest predictor of employment for young autistic adults' post-school was engagement with life and employment skills during secondary school years.

One area of program structure that Bruce's mother described as critical was the school staff's attitudes towards the inclusion of young people on the autism spectrum and their willingness to support student needs while at school. She described a mostly positive experience during Bruce's time at school: "The head of the special education unit at the time, she was a brilliant lady. She had such a heart for it, and all of her staff were the same, they had such a heart for it." She went on to describe the importance, from her perspective, of the teachers' attitudes towards working with autistic students. She stated, "You know when you go to meet teachers, when they're sitting like this [leaning forward, smiling], you know they're keen to help you. If they're like this [back straight, no smile], forget it", although Bruce's mother was clear in her statement that "The main influence on culture was really the administration team", and thus school culture had changed many times over the years depending on the administration team at the time.

Another area that Bruce's mother found frustrating at the time was a perceived level of segregation between the mainstream school and the special education unit. She remembered how, "It's a funny thing, even when Bruce was there, the administration's attitude to the special education unit and the kids – it was your kids. That was probably the only negative thing." She explained that "If anything happened, they would come back and say, 'Oh, your kids did this' and we would have to remind them, 'Don't you say that … It's the whole school'." Thus, despite what Bruce's mother described as a positive experience with school staff, there was still a divide evident where the students who attended the special education unit were perceived as being members of the unit, rather than members of the school.

Bruce's mother did express a level of understanding of the difficulties faced by schools in catering for the individual transition needs of students on the autism spectrum, or any student supported by the special education program. She explained, "When Bruce started, they had 10 kids in the special education unit. When I left, they probably had 80 – 90 kids that they were trying to work with. The numbers, they just exploded." This higher number of students was seen by Bruce's mother as a serious problem for schools trying to meet the individual needs of students, and being able to provide the life skills, employment skills, and social-emotional skills that the students needed to transition successfully from school to post-school options. She stated, "They need to appoint somebody out here as the coordinator to organise all that [transition planning and implementing these plans]" (see also Lee & Kim, 2021).

7.10.6. Interagency Collaboration

From Bruce's mother's perspective, the interagency collaboration that occurred when Bruce attended secondary school resulted in positive outcomes for the students; however, she acknowledged that much of this no longer occurred. An example shared was working with the Queensland Department of Transport and Main Roads to help the students to obtain their driver's licence. Bruce's mother described how "We'd take them down to help them to get their licence. We'd take them down, we'd get the books, we'd practise it at school. We had certain times of the day or the week that we'd do that", then the students "Went to [the main town in the region] and did the defensive driving course." For the students, obtaining their learner's driver's licence at school and being supported to learn to drive safely resulted in a high level of independence for the students once they left school and were able to get their full driver's licence. Bruce emphasised the importance that his licence provided, allowing him the independence to be able to go where he wanted or needed for work or personal needs.

Another area of high collaboration occurred between secondary school and the local TAFE, with students at the school enrolling at the TAFE and completing work qualifications while still at school. Furthermore, studying at the TAFE contributed to the student's Queensland Certificate of Education. Bruce's mother described how "Kids that have gotten a traineeship, they will work a day a week at the traineeships, maybe go to TAFE one other of those days, and they've got three days at school." Thus, students were continuing in their education, while at the same time gaining both qualifications for employment in their area of interest and experience in the workplace, both of which are key predictors of gaining successful employment as an adult (Pillay & Brownlow, 2017; Wehman et al., 2015).

7.11. Piper

7.11.1. Introduction

Piper attended a metropolitan Christian secondary school and graduated approximately three years prior to the interview. Piper's mother described how "Piper chose her high school. We let her make that decision because we believed it was really important." Both Piper and her mother described her high school experience as mostly positive and stated that “There was a lot of support”. Despite this high level of support throughout her secondary school experience, Piper still felt that, when she finished school, “It was like a wave and then a shut the door to your face.” Piper’s experience of transition from school to post-school was that school was one period in her life and, when it ended, everything needed to “start again”.

7.11.2. Student-focused Planning

Piper and her mother both described a high level of involvement in planning and monitoring Piper’s secondary education, although both felt that “We had a plan through Year 12, but no transition plan.” The focus of these plans was seen by Piper to be very much on succeeding at school, with little planning for what would happen after graduation. Piper’s mother agreed with this, indicating that “We had multimodal planning. So, we had her normal learning plan. And then in Year 10, we changed it to accommodate all the Year 12 stuff … We also had meetings about the end of semester reports, about how it was going. But there was no transition planning.”

Part of this planning process included the development of the SET plan, and, as with other participants, this was perceived by Piper and her mother as primarily subjection selection: “That was all about what subjects suited. But she already knew at that stage; she was like, ‘I’m going to do these because it’ll give me the best options.’” Piper and her mother expanded on the discussion about the SET plan, indicating that “We noticed that in the Year 10 SET planning, which incorporated her personalised learning plan, there was a very heavy push to a non-OP pathway.” The overall position (OP) score pathway provided Queensland school leavers with a tertiary entrance score that was used to determine whether the student could apply for and attend tertiary education after completing secondary school. The “heavily inferred” non-OP pathway presented to Piper would have meant that she was not eligible to apply for university at the end of Year 12. Piper emphasised, “But straight away I was like, ‘No, I'm not doing that. Because I didn’t want … I knew that I could do it’.” Piper’s mother similarly indicated that “We were like, ‘Well, no, she wants to do it. So, we’re 100% supportive’.”

Regarding her level of involvement in the planning process, Piper stated that "I was part of [developing her learning plans] … not all of them, but most of them." When I asked Piper if she received any training on self-determination to encourage her participation in the planning meetings, she stated, "No, because I think they already knew I was like that. I was pretty independent, and I didn't like interference from teachers and mum and dad." Piper's mother spoke about Piper's level of participation in the planning meetings, indicating that "I know that Piper will feel like there wasn't a lot of preparation, but a lot of it went on behind the scenes. Some of it just because that's how it happens, but some of it because it was purposeful to avoid her being embarrassed or singled out."

One area that Piper indicated that she did not feel supported by the school was with the decision about what she would study at university. She explained that "It wasn't like I'd known all my life. So, it was like, 'It's time, I've just got to pick something'." She indicated the school's response was, "Oh, well, you just pick something and just try it." Piper went on to state that "I kind of had Jason [her boyfriend] and mum to help me with that, but I didn't really have like the school support."

7.11.3. Student Development

A key aspect of student development is teaching life, social, and emotional skills. As with the other participants, a focal point of discussion for Piper and her mother related to the social and emotional aspects of school, how the school addressed these areas, and the impact that this had on Piper as an adult. Piper indicated that "I always tried so hard to like hide it [social difficulties in secondary school]. Because I got a lot of crap from that in primary school: 'Oh, you're the teacher's pet. You're the favourite.'" She went on to describe how "I didn't feel appreciated, and I didn't like being like that, you know, person who was different." As a result, when Piper started secondary school, she made the decision to change:

> I didn't want to look or appear different … Because no one really knew me, I wanted to like change who I was. It wasn't necessarily like faking who I was, but it was … I didn't want to be that person anymore, and I wanted to be, you know, me but liked.

This statement indicated that Piper used significant levels of social masking throughout secondary school (Lai et al., 2017). While Piper suggested that she did not experience social or emotional difficulties during high school, anxiety was a key discussion point in Piper's perception about her QoL after transitioning to post-school. This experience described by Piper reflected the experiences of autistic adults in the study conducted by Raymaker et al. (2020). That is, high levels of prolonged social masking, combined with the increased expectations following the transition to adulthood, often result in heightened levels of anxiety during this period.

Despite her improved social status at high school and Piper referring to herself as "part of the popular group", Piper and her mother still described how Piper experienced serious bullying during secondary school. Piper's mother indicated, "Piper had so many social struggles during high school. I'm not talking about like normal banter or normal mucking around and picking on, but like actual serious internet bullying, character defamation, total social isolation at school." Piper described how one of her classmates "spread a rumour around that I had been sending inappropriate photos to guys" and, because people believed it, "I lost all my friends and my boyfriend at the time. I was 15. That was like really embarrassing because that was like defamation of character." Piper went on to state, "So then I stopped going … I refused to go to school. Because it was so awful [the bullying]." Piper's mother explained that at this point she stepped in, contacting the school, and saying, "You need to stop this right now." Fortunately, the school "Went through the restorative justice process" and "The other girl came and asked forgiveness and so did all her friends"; thus, Piper found "The second half of Year 11, and then Year 12 was like almost normal." The school's direct intervention and support of the social-emotional wellbeing of students in the face of serious bullying resulted in positive outcomes for everyone. In turn, this allowed Piper to continue to experience positive social relationships throughout her secondary schooling and helped Piper to develop a mature, positive sense of self regarding her social relationships (as described in Chapter 5). The negative side, from Piper's mother's perspective, was: "I think what happened then was that, when those things settle down, they kind of thought, 'Well, she's going okay so she doesn't need those extra things.' As far as emotional support leading up to the end of Year 12 and entering university, she didn't really get any help.” This was despite the “social and emotional support written into her learning plan”.

The final area of student development discussed by Piper was encapsulated in the statement, “I wish I’d been taught everyday stuff [at school].” Piper indicated that she was not provided with sufficient life skills while at school, making statements throughout the interview such as:

> I wish I learned really practical stuff … I wish I had got told how to apply for houses you want to rent … I wish I’d learned about finances and been told that if I did a certificate, if I had the time during high school, then I could get a good-paying job while I’m studying.

Piper discussed how not having this knowledge increased the difficulties that she experienced during the transition from school to post-school, increased her reliance on her family, and increased the level of stress experienced during the transition.

7.11.4. Family Involvement

Throughout the interview, Piper’s mother described a high level of involvement in the daily school program. This included involvement in the development of Piper’s learning plans: “Generally, they wrote the plan and they asked us what we thought she needed”, and in the assessment of the plan implementation and outcomes: “I would sit there and go, ‘Well, what about this, and how come they haven’t made this adjustment, and I don’t see that reflected?’” Piper also remembered this occurring:

> Mum would be in the meeting with my case manager, and we would look through them all and read them all. And then mum would be like, ‘Oh I’m not happy with that because that doesn’t reflect her learning plan’, and then my case manager would go and talk to the teacher about it more.

Despite this high level of involvement in the daily school program and supporting Piper to succeed at school, Piper’s mother still indicated that, “Even though we had these plans, there was no transition planning.” Instead, Piper and her mother felt that the school plans were developed for school, with no consideration of what was to come after school. This viewpoint was shared across all the transition programming domains. For example, although Piper's school plans were student-focused, the focus was on school outcomes rather than on transition outcomes, and, while student development focused on developing and supporting skills for school, it did not consider the skills required beyond school.

Piper's mother also spoke about the differences in collaboration with each of her children, with Piper being the oldest. She stated, "It wasn't as collaborative as it is now. Now I would go about things very, very differently. I would probably be a bit more outspoken now, if I had to do it with Piper again." Like Helen and Anne's mother, Piper's mother indicated that the process of collaborating with schools was something that became easier the more that you did it, and the more that you learned. Together, these statements highlighted the importance of family preparation for working collaboratively with schools (Kohler et al., 2016). That is, families require support to be able to collaborate effectively with school staff, and equally, school staff require support and training to be able to collaborate effectively with families (Kuo et al., 2017). Piper's mother summed this up with the comment, "They [schools and parents] don't know what they don't know."

7.11.5. Program Structures

Piper's perception of program structures was shared across two key areas: teacher support, and the importance of inclusion. Piper spoke very positively about the level of support provided by her teachers throughout high school, stating, "I could always go to the teachers if I didn't understand something." She explained that "I had lots of drafts with assignments. Usually, we were only allowed to have drafts to be checked once, but I was able to have them checked often." Furthermore, "I would have specific feedback from each teacher as to why they had graded me that way. That's how I kind of like learned, was from feedback." Piper's mother supported these statements with the comment that "There was a lot of support planning for Year 11 and 12, those assessments." This high level of support and feedback allowed Piper to achieve the grades needed to move into tertiary education after school. Piper's mother did, however, express some concerns regarding teacher support: "We started to see inconsistencies between teachers. Then we had to address the fact that maybe the learning plan wasn't given to every teacher across each term and, even when they were, each one interpreted the plan differently." This comment linked back to the previous section (Section 6.11.4), where it was stated that high levels of family involvement in the review process allowed a more consistent level of support to be provided across staff and subjects.

Although Piper shared that “The teachers are very good, in the sense that if you do have ASD they tried to help”, she admitted that she was reluctant to seek this support because she did not want the other students to know that she needed it: “I tried to hide it in the sense that I didn’t want to talk about it, I didn’t want to particularly show that I needed extra help. And I didn’t want teachers coming up to me and favouring me.” This tension between appreciating and needing support, and not wanting to be seen to be different, was also expressed by Piper in the example that she provided about exam rooms. She explained, “The whole grade would go for exams, and then the separate room was here. It wasn’t really hidden, you know. You could tell we were going into a separate room. It was really obvious.” While Piper admitted that “Being in a different exam room could have made it more difficult if it was only one person and they were struggling to make friends”, her experience was that “There was a few people that were in the same popular group going in there, so it made us all feel better about it, and it also made everybody else … like normalise it because they were all their friends,” Thus, Piper shared that how supports are offered is important to ensuring that students feel included, rather than excluded (see also Saggers, 2015).

7.11.6. Interagency Collaboration

The importance of interagency collaboration was shared by Piper and her mother in relation to career selection and the process of enrolling at university. Piper shared that as a student at school she was provided with “Heaps of talks and careers advice and stuff like that. They would have parents come and talk about their careers. They would have the past students come and talk about what they were doing.” However, when the decision about what she would study at university needed to be made, Piper felt that “I didn’t really have the school’s support.” Piper did state that she was assisted through the school to fill in and apply for early acceptance to university, but, from her perspective, that was the end of the support provided for her transition to university. She expressed frustration that “There was time for me to have that extra help considering I had already gotten in”, but that this support was not forthcoming. Piper’s mother also mentioned this lack of support, suggesting, “That [early acceptance to university] took the pressure off, but it still didn’t really help with the accessibility. We had to go and do all that research ourselves.”

Piper did share that “I spoke to the teacher that does all the careers after I found out that I was eligible for a learning plan. And then he helped me … He met with me at lunchtimes and helped me [to] fill out the form to request a learning support plan at university.” However, she stressed that this was something that he did in his own time, and not as part of the support typically provided by the school. When questioned as to what may have helped with this transition, Piper suggested: “practical stuff”, “Going to the university and having a buddy and doing classes with them”, and “Having people that are past graduates come in and explain what they do now and what it’s like for them now, and it was like for them when they graduated” (see also K. A. Anderson et al., 2018; Anderson et al., 2020). She also suggested the importance of having students on the autism spectrum, or with disability, represented in those people who did speak to the students about transition experiences: “Even when we had speeches, they didn't say anything about having learning plans. So, I didn't even know that I could have a learning plan.”

7.12. Chapter Summary

Chapter 7 has provided rich descriptions of the perceptions of the nine young autistic adults, and their parents, about their experience of transition planning and how this impacted on their current QoL. The adults’ perceptions were reviewed in relation to the five recommended transition practices according to the TTP framework: student-focused planning, student development, family involvement, program structures, and interagency collaboration. Furthermore, how these transition practices impacted on current QoL was shared. The use of participant voice was highlighted throughout, with the use of direct participant quotations to describe their perceptions.

Overall, the young adults and their parents perceived the transition practices of secondary schools as poor. The current transition planning process was seen as little more than subject selection and did not meet the requirements of student-focused planning, especially in the areas of student participation and building transition plans based on the students' individual strengths and needs. This resulted in many of the young autistic adults having experienced a disconnect between their actual post-school goals and the goals achieved through secondary school. Student development was also seen as failing to teach the students many of the specific skills required when they transitioned to post-school to pursue tertiary education, employment opportunities, and independent living. Again, this resulted in many of the young adults experiencing a gap where their families and adult support services were required to teach these skills to maintain progress. Interagency collaboration, particularly between secondary schools and adult services and organisations, was considered ineffective by all participants and their parents. For most participants, this resulted again in a gap between school and post-school, where the young adults and their families were required to "start again" to put into place the required supports to ensure a positive QoL.

The level of family involvement in school-based transition practices was very low, especially when compared to the level of family involvement in planning and implementing school to post-school transitions outside school-initiated transition planning. While parents were actively planning and implementing the transition to post-school options, this was done with little involvement or knowledge from the schools. Thus, greater levels of collaboration between schools and the young people and their families are required. Finally, these poor school-based transition practices were underpinned by a lack of legislation and policy guidelines within the Queensland educational context. This lack of policy guidance, in turn, resulted in poor transition practices. Even when schools and families attempt to implement effective practices, they are hampered by issues related to resourcing.

CHAPTER 8: SECONDARY SCHOOL TRANSITION PRACTICES CROSS-CASE ANALYSIS

8.1. Chapter Overview

Chapter 8 introduces the cross-case analysis of the transition practices experienced by the young autistic adults during their last years of school, responding to Research Question 2: ***How and why have secondary school transition practices influenced the quality of life of young autistic adults?*** These experiences were presented within the five domains of the Taxonomy for Transition Programming (TTP) framework: student-focused planning; student development; family involvement; program structures; and interagency collaboration (Kohler et al., 2016). Similarities and differences shared between the cases were used to support the overarching themes presented within the five domains. Although the TTP framework is not mandated within Australian and Queensland educational contexts, it has been suggested as an appropriate transition-focused educational framework for use in Queensland schools (Beamish et al., 2012). Furthermore, it provides practitioners with predetermined practice standards against which current practice can be benchmarked.

The conceptual framework (see Chapter 3) was used to guide the cross-case analysis of transition practices. Thus, themes within each TTP domain were considered in relation to self-determination theory (SDT) and a biopsychosocial model of disability. As discussed in Chapter 3, student-focused planning and student development are key supports for individual factors supporting young autistic adults transition to post-school. That is, the use of these domains within transition planning assists with the development of the skills, knowledge and attitudes required to move into post-school life and to achieve the goals and aspirations of the individual. Family involvement, program structures, and interagency collaboration provide the key environmental supports for the young people as they progress through a transition to post-school. Thus, all five of the domains are critical to ensuring the consideration of both individual characteristics and environmental supports in school to post-school transition practices (Kohler & Field, 2003).

To present information across the five TTP domains, deductive coding was used first to categorise information shared regarding transition practices into the five TTP domains. Inductive coding was then used to determine the key themes across each domain (Miles et al., 2014). These inductive codes led to the development and recognition of the key findings relating to the young adult's perception of the secondary school transition practices they experienced. From this analysis, the following key findings were identified:

- Transition practices across schools were inconsistent.
- Across cases, most young adults had not been involved in student-focused planning during their secondary schooling.
- Student development was strongly focused on academic achievement with living, social, emotional, and work-based skills addressed for some young people, but not for others.
- There was a lack of strategies and support for social and emotional wellbeing during secondary schooling.
- Family involvement was limited and did not include family empowerment or family preparation for transition.
- A positive school climate, allocation of resources, and flexible program characteristics were considered critical by all the young adults and their families.
- Limited policies and procedures, strategic planning, and program evaluation impacted negatively on all aspects of transition planning in secondary schools.
- There was limited interagency collaboration between schools and most other organisations and agencies, and schools were not sharing information about other organisations and agencies with young people or their families.
- Interagency collaboration between schools and Technical and Further Education (TAFE) campuses was promising.

The remainder of the chapter will discuss the cross-case analysis of the young autistic adults' perceptions of secondary school practices within the 5 categories of the TTP framework. This cross-case analysis will show how the above nine key findings were determined.

8.2. Student-Focused Planning

The experiences of the young adults interviewed varied considerably regarding student-focused planning, although, from the perspective of most young adults and their parents, the Senior Education and Training (SET) planning process was described as a "one-off event" for "subject selection". That is, the focus of SET plans was to select subjects for the senior years of secondary school, with the suggestion that students should select subjects that were aligned with what they wanted to do post-school. Thus, student-focused transition planning was not experienced as a positive process that encouraged student engagement, taught decision making or planning skills, fostered self-determination, or was focused on establishing post-school transition goals. Additionally, there was little monitoring or evaluation of these plans and whether these plans continued to be appropriate.

For the small number of young people interviewed who had clearly identified plans to move into tertiary education, the process of subject selection as a form of transition planning suited to at least some post-school goals. For example, Eric knew the university he wanted to attend and the program in which he wanted to enrol, so "choosing the right subjects and getting the highest marks possible" for Eric were considered an effective approach to transition planning (see also Wong et al., 2021). There were also positive examples of student-focused planning leading to employment related qualifications in an area of interest. These included John and Tamara both attaining a TAFE level qualification in industries where they saw themselves working post-school. Alternatively, for those young people who did not have a clearly identified plan for post-school options, the SET planning process was described not only as ineffective, but also in many cases as damaging to transition planning and post-school outcomes. For example, from John's mother's perspective the SET planning process limited his post-school options, and from Anne's perspective the SET planning process had resulted in a rigid and ineffective senior secondary education program that, in turn, led to increased stress and anxiety during the final years of school (see also Chandroo et al., 2018). For the older autistic adults interviewed, Bruce, Paul, and Frank, the IEP process was equally identified as not teaching component skills of self-determination, nor as resulting in working towards any specific post-school goals chosen by the individual.

Student-focused planning is seen as a key pillar of effective transition practices (Kohler & Field, 2003). Effective student-focused planning involves the participation and engagement of young people in making decisions and in planning for, monitoring, and evaluating their individual goals for their secondary education and post-school options (see Table 7.1). A critical aspect of student-focused planning, according to Kohler (1996), involves the teaching of component skills: effective communication, breaking goals into small, achievable steps, the evaluation of progress and determining next steps. Furthermore, these component skills and their implementation are considered fundamental to the development of self-determination. Snell-Rood et al. (2020) demonstrated that teaching these component skills supported students with disability to engage in student-focused planning, and Shogren and Shaw (2016) and Shogren et al. (2017) demonstrated that this in turn increased these student's self-determination both during and after school. Despite this, research conducted by Chandroo et al. (2018, 2020) consistently indicated that students on the autism spectrum in Australia engage in transition-focused planning at a basic level, rather than at a self-determined decision making and planning level. Moreover, O'Neill et al. (2016) found that student-focused planning was poorly represented in Australian national and state policies, indicating that Queensland schools are provided with limited support or encouragement for ensuring that students on the autism spectrum engage in student-focused planning.

Thus, the first theme identified in student-focused planning was that *the **Senior Education and Training (SET) planning process was perceived primarily as one-off subject selection,*** rather than as a process of teaching skills and making decisions to support students on the autism spectrum as they worked towards transitioning to post-school options. This was suggested by the majority of the participants and was supported by the analysis conducted by O'Neill et al. (2016), who found that student-focused planning was one of the least represented TTP domains within Australian educational policy.

The second theme identified across cases was that ***current transition planning practices do not typically support the individual autistic student's strengths and interests.*** There were some examples of the positive integration of strengths and interests for the young adults interviewed. For example, Eric received significant support for his goal to attend university. Similarly, both John and Tamara were encouraged to follow their respective interests in hospitality and early learning, and their programs included TAFE qualifications in these areas, although John's mother stated that she did not believe that his interests would have been followed had it "been something less common" or something that the school was not already providing for other students.

All the other participants, however, experienced some form of mismatch between their strengths and interests and the plans used to focus their last years of schooling. For example, Helen was not encouraged to pursue her strengths in art, while Anne's passion for history was discouraged. In both cases, Anne and Helen felt that they were pushed more towards options that would get them "a job". Piper shared that a non-OP pathway was "heavily inferred", while Frank was not provided with the option of working towards "getting a trade", something that he very much wanted. Bruce was provided with work experience in the aircraft industry; however, it was his family who organised for that to continue. Although the school allowed Bruce to have this work experience time away from school, they did not include this as part of Bruce's educational program. Finally, Paul was not encouraged or supported to follow his interest into the meteorology/climatology industry.

These mismatches are concerning given the significant role that strengths and interests played in the QoL of the young autistic adults across domains (see Section 6.6.6; see also Grove et al., 2018; Wood, 2021), and that an "important aspect of student-focused planning is that educational decisions are based on students' goals, visions, and interests" (Kohler & Field, 2003, p. 176). In the TTP framework, it is generally intended that the young person's strengths and interests are given considerable weight so that students are provided with vital opportunities for the development and application of self-determination, including autonomy, competence, and relatedness (Ryan & Deci, 2017). Thus, limited student-focused planning is likely to result in limited development and application of self-determination as the young person transitions into post-school options.

8.3. Student Development

Two themes were found across cases with regard to student development. The first was ***that schools were perceived to have a strong focus on academic skills with limited opportunities for the development of life, employment, or social-emotional skills*** (see also Wong et al., 2021), although the *support for student development varies significantly between schools* (see also Beamish et al., 2012). Student development as a domain within the TTP framework is a key area where students develop the "academic, living, social, and occupational skills; career awareness and work-related behaviours" (Kohler & Field, 2003, p. 177) needed for transition to the post-school options of tertiary education, employment, independent living, and interpersonal and community engagement. Furthermore, Kohler and Field (2003) stated that an important part of the process of student development is the use of assessment to identify correctly the skills that students already have and the skills that they need to work towards competence in these areas. Alarmingly, Cumming et al. (2020) found that assessment to identify current and needed skills across student development was the "least discussed topic" (p. 8) by both teachers and parents, and similarly, the findings across cases indicated that assessment to identify current and needed skills was not mentioned by either the young adults or their parents. Rather, it was suggested that some schools provided general programs or classes in academic, living, social, or work-related skills that students on the autism spectrum could access, while some schools did not offer these programs or classes at all. For example, Anne and Helen both shared that, while the school timetabled "life skills classes", they described them as "free periods" for students to complete assessments from other classes or to do nothing.

Tamara, Bruce, and Paul spoke positively about being provided with supports for the development of everyday living skills such as shopping and cooking, and all three indicated that these skills had been beneficial during their post-school life. Interestingly, all three young people attended small regional schools, although the connection between these two factors could not be established by this research. Frank did mention learning about cooking while attending the special education unit, although both Frank and his mother felt that these skills were too basic, such as "Making a sandwich", and did not go far enough to support independent living. All other participants shared that they were not provided with any instruction or support related to daily living skills, and that all the living skills learned, both during school years and post-school, had been taught by parents.

An important aspect of daily living skills discussed by all the young adults interviewed was the difficulties experienced in understanding and managing finances, and the important role that this played in their post-school QoL. Furthermore, all the young adults indicated that this was something that they were not taught at school, but that it was something that they believed could have been addressed more effectively (see also Cheak-Zamora, Teti, Peters, et al., 2017). Daily living skills, including financial capabilities, have been found to be fundamental to the outcomes experienced by people on the autism spectrum in relation to tertiary study, employment, independent living, and most importantly self-determination (Baker et al., 2021; Hewitt et al., 2017; Ward & Webster, 2018), yet the participants in this research indicated that there was limited teaching of daily living skills to students on the autism spectrum.

Some participants mentioned aspects of developing career awareness and work-related behaviours; however, again these were inconsistent and did not relate to person-centred support. Helen, Anne, Bruce, and Tamara all mentioned attending work experience during their secondary schooling. For Tamara and Bruce, the work experience that they mentioned was positive and led to positive outcomes, with Tamara gaining a school-based traineeship and Bruce continuing work experience at the company. For Helen and Anne, their work experience options were not related to their interests, and both shared negative experiences where the work experience was not matched with their skills. For example, Helen shared, “I was put on front counter greeting people and answering the phone”, which she identified as skills with which she struggled owing to her experience of autism. Similarly, regarding career development, some participants spoke about talking to the “guidance counsellor” for career advice; however, all those who did so indicated that it was not helpful. Thus, schools offered some programs and options to all students; however, none appeared to offer specific, tailored support in developing skills for students on the autism spectrum related to improving post-school outcomes in employment. This was despite the consistently reported difficulties experienced by this population with gaining and maintaining employment (Farkas et al., 2021), and the substantial amount of research indicating the importance of work-related skills for successful post-school employment (Pillay & Brownlow, 2017; Wehman et al., 2015; Wong et al., 2021).

Finally, and most importantly given the social and emotional outcomes described by the young autistic adults (see Section 6.6.2), no young adult described specific, targeted development or support in the areas of social or emotional skills or wellbeing during their secondary schooling. Conversely, most participants spoke about the significant social and emotional difficulties experienced during their time in school. Helen, Anne, Bruce, Piper, Tamara, Frank, and Paul all spoke about the difficulties that they experienced with bullying during school and the impact that this had on their social and emotional wellbeing (see also Adams et al., 2016). Furthermore, all shared that they felt that their schools provided limited support regarding the bullying that they experienced. Only two participants, Tamara and Eric, described the positive social and emotional support provided by their respective schools. Tamara described the school-wide program, Strength and Character Groups (SCG), that she felt supported an overall positive school climate and social interactions, and she also spoke about teachers recognising her difficulties in making friends and supporting her in trying to develop friendships. Eric and his mother spoke about the positive school culture and the high level of autonomy provided to the students and the positive social and emotional outcomes arising from this.

With social communication differences being a core characteristic of autism (American Psychiatric Association, 2013), and with significant research indicating the emotional difficulties and poor mental health experienced by the majority of autistic adolescents and adults (Autism Spectrum Australia [ASPECT], 2013; Bishop-Fitzpatrick et al., 2018; Spain et al., 2018), this lack of social-emotional development and support in secondary schools is extremely concerning (Aubineau & Blicharska, 2020). Moreover, the lack of specific, targeted student development indicates that schools are failing to meet the need for autonomy, competence, and relatedness across the student development domains for young people on the autism spectrum (see also Ryan & Deci, 2017), despite the high levels of expectation within Australian educational policy for student development (O'Neill et al., 2016).

8.4. Family Involvement

Kohler and Field (2003) included three aspects within the domain of family involvement in transition-focused education: family involvement; family empowerment; and family preparation. All three factors are considered supportive of student outcomes, both within the school context and as the young person transitions to post-school options. The domain of family involvement, however, is one that has inconsistent support within the Australian and Queensland school contexts. O'Neill et al. (2016) found that family involvement was poorly represented in both national and state educational policies. Despite this, Beamish et al. (2012) reported that Queensland school educators strongly endorsed family involvement as a practice and considered this an area of strength. Specifically, educators highly valued family involvement in planning processes, and in meeting and providing families with transition aims and options. Despite this high value, it was also found that "participants in this Queensland study were reticent about empowering parents to be equal or leading collaborative partners in the transition planning process" (Beamish et al., 2012, p. 238). In this research, both these findings were supported.

The young adults and their parents indicated that ***family involvement in school transition planning was limited to day-to-day communication and developing the SET plan,*** with significant variability in the level of family involvement across different schools. Bruce's mother described high levels of family involvement; however, she linked this to her working as a teacher aide at the school that Bruce attended, and she indicated that this involvement related more to school-based decisions than to transition-focused planning. Similarly, Piper's mother also indicated high levels of family involvement in decision making and planning regarding the daily school program; however, she stated that "there was no transition planning". All the other parents indicated poor levels of family involvement in both the daily school program and the transition planning, with some, especially Helen and Anne's mother and Frank's mother, indicating that even communication regarding the daily school program was difficult and not supported by the school. For some parents, they felt this was their own choice; for example, Eric's mother stated that she "disengaged" because Eric knew what he was doing and school was going well, while John's mother also indicated that "things were going well", so greater levels of involvement in the daily school program were not needed. These findings supported research conducted by Goldman et al. (2019), who indicated that parental involvement decreased as students moved into secondary school, and that at this level of schooling the key involvement of parents was in relation to difficulties that their autistic adolescent was experiencing at school. Concerningly, these findings indicated that, when students were not experiencing difficulties at school, family involvement was considered unnecessary, and that, when students were experiencing difficulties at school family involvement was discouraged or unsupported. Either way, across cases most families experienced minimal engagement in the daily school program, while all families experienced minimal engagement in terms of transition-focused education other than attending one SET planning meeting. Taken together these findings further supported the initial indications that, while schools and educators value family involvement in the planning process, developing the SET plan, the more empowering practices related to families leading decision making, family empowerment, and family preparation and training were less supported (Beamish et al., 2012). Furthermore, "parental attendance at meetings did not always translate into meaningful collaboration" (Beamish et al., 2012, p. 238).

Although engagement in school-based transition-focused education was poor, ***many families were engaged in transition planning outside the school environment.*** Findings from this research indicated that family involvement in the transition planning process was very high; however, this typically occurred separately to school (see Section 6.6.3). For example, Frank's mother stated, "I planned it [the transition to post-school]", and Helen and Anne's mother indicated that "we've done all that", referring to the girls' transition to post-school options. When the family transition planning and school transition planning did overlap, it was a case of the parent telling the school what had been implemented and the school allowing this to occur. For example, John's mother found and set up work experience as part of John's school week, while Bruce's mother organised Bruce's work experience to continue past the school's timeframe. In both cases, while the school allowed this to occur, the parents stated that there was no attempt from the schools to extend on these experiences as part of the school program. As John's mother stated, “They thought that we were doing something, and it was good and that was that”.

These findings supported previous research that indicated that the primary responsibility for transition planning falls to the young adults and their parents. Hatfield et al. (2017) found that parents felt that the transition planning process was their responsibility, while Ruble et al. (2019) shared families’ perceptions that plans to achieve postsecondary outcomes were left to students and their parents to implement instead of to educators. These findings indicated a significant disconnect between school-based transition-focused education and family-based transition planning. Given the considerable body of research indicating the value and importance of the two, school and family, working together (Goldman & Burke, 2019), and the expectation within Australian education that this will occur (Education Council, 2019), a significant problem has been highlighted through these findings. Furthermore, Kohler and Field (2003) indicated that student-focused planning and student development are supported and extended through family involvement; therefore, the existing difficulties with family involvement in transition-focused education for these families were likely to have contributed to the inconsistent and reduced levels of student-focused planning and appropriate student development experienced by the young autistic adults in this study.

The value of family involvement in improving educational outcomes for all students is widely accepted throughout educational research, with perceived benefits for students in terms of engagement, wellbeing, and achievement (Goldman and Burke, 2019). Although the same level of research is not available in relation to family involvement specifically for autistic students, initial indications are that family involvement in school, and in particular in transition-focused education, is even more important for autistic students (Goldman & Burke, 2019; Shogren & Plotner, 2012). It must be noted that the focus of the majority of studies of family or parental involvement for autistic students has been conducted within special education services, rather than in mainstream settings (Goldman & Burke, 2019). Thus, the findings of this research add significantly to the knowledge base of family involvement in mainstream settings for students on the autism spectrum.

8.5. Program Structures

The domain of program structures includes multiple program features, including program characteristics, program evaluation, strategic planning, policies and procedures, resource development and allocation, and school climate. All these features are considered a critical part of the program structures provided within broader educational systems and specific school contexts (Kohler & Field, 2003). The young adults and their families spoke about three features related to transition planning: program characteristics; resource allocation; and school climate. All the other aspects of program structures were not mentioned by the young adults or their parents. This finding, in and of itself, was significant as it indicated that the young people and their families were not aware of the policies and procedures, strategic planning, or program evaluation that occurred in relation to transition-focused education. It also supported findings of previous research that indicated a similar lack of awareness by parents and families of young adolescents with disabilities around these features of program structures (Cumming et al., 2020), despite the inclusion of references to the importance of these features in current Australian educational policy (O'Neill et al., 2016).

From the view of the young adults and their parents, ***program characteristics were perceived as rigid and inflexible, particularly within mainstream classes.*** Greater levels of flexibility were provided within special education programs as evidenced by examples from John, Tamara, Bruce, and Paul. These participants spoke about the daily living, social, and work-related skills accessed throughout their school program, and Tamara and John felt that the school program was tailored to their strengths, interests, goals, and aspirations. Even with these supports and adjustments, however, Tamara still spoke about the lack of flexibility within her mainstream classes, and the “crammed curriculum” within the overall program. Frank also attended a special education program (SEP); however, his experience of the program being inflexible was that he attended only SEP classes and experienced no inclusion in the mainstream school. From Frank and his mother’s perspective, the classes and curriculum offered within this program were neither suited to Frank’s needs nor tailored to his strengths, interests, goals, or aspirations, resulting in an overall negative experience of school. The other participants who all attended mainstream classes – Anne, Helen, Eric, and Piper – all emphasised the academic expectations within the school program, and viewed classes and curriculum as *set* rather than as *flexible*. For the young adults who had already chosen to follow an academic path, this was not a difficulty. For example, Eric shared the importance of “choosing the right classes” and of “getting the best grades you can”. However, for those young adults who were not as confident in their post-school choices, this lack of flexibility caused significant distress. Thus, although some special education programs appeared to provide a greater level of flexibility for students, these findings also highlighted the importance of inclusion in mainstream classes. Furthermore, the findings indicated a critical need for greater flexibility within mainstream classes and curriculum for some students (see also O'Neill et al., 2016). In turn, this supported the importance of student-focused planning and of the assessment of student strengths and needs within student development (Chandroo et al., 2020; Kohler & Field, 2003) to ensure that educational programs suit individual student requirements.

Resource allocation was considered a critical point within program structures, as the young adults and their parents viewed resource allocation as the vehicle through which this flexibility could be provided. Several parents, including Helen and Anne’s mother, Bruce’s mother, Tamara’s mother, and Piper’s mother, all spoke about the importance of appropriate human resourcing, including staff who were knowledgeable about and supportive of students on the autism spectrum. At the same time, all shared a belief that schools are under-resourced and that many staff do not have the required knowledge and understanding about autism, nor are they provided with opportunities to develop this. Tamara also spoke at length about the importance of “good teachers” and indicated the clear difference that she felt was achieved through teachers learning “how to work with kids like us”, while, for Anne and Helen, limited teacher understanding and knowledge about autism had a negative impact on their experience. Both Tamara’s and Bruce’s mothers emphasised the value of teachers with personal experience of autism and the value that this lived experience provided in the educational context. This perception supports the contemporary belief that the knowledge gained through the lived experience of autism is critical in effectively supporting people on the autism spectrum across all life contexts (Bottema-Beutel et al., 2020; Pellicano et al., 2019; Spath & Jongsma, 2020).

The primary perceptions shared by the young adults and their parents related to school climate, with ***a positive school climate and school connectedness suggested to be key enablers of positive school experiences for students on the autism spectrum.*** School connectedness refers to "the degree to which the young person believes they are valued and appreciated by others in the school community" (Shochet et al., 2021, p. 17) and included the sense of connectedness that the young person felt to the staff and to peers within the school environment. For the young adults, this very much determined their overall perceptions of their school experience. Those who experienced positive school connectedness viewed their school experience and the transition from school to post-school more positively, while, for those who did not have this experience of positive school connectedness, both school and the transition from school were experienced as more difficult. John, Eric, Piper, Bruce, Paul, and Tamara all shared a more positive sense of school connectedness, including important staff and peer relationships, with comments such as "I had good friends" and "The teachers were good". Moreover, all had experienced more positive outcomes across QoL domains as they transitioned from school to post-school options. Conversely, Frank, Anne, and Helen described greater difficulties with school connectedness, including a lack of staff understanding and peer conflict, and all experienced poorer outcomes in QoL during the school to post-school transition.

The critical role of peer acceptance and peer relationships in positive wellbeing was well supported (Roach, 2018), and the importance of social interaction and acceptance for young people on the autism spectrum has been evidenced across research (Cribb et al., 2019; Mattys et al., 2018). Thus, the importance of positive peer relationships, as a critical part of school climate and school connection, for young people on the autism spectrum during their school years is evident (see also Carrington et al., 2021; Shochet et al., 2021).

Similarly, Osborne and Reed (2011) found positive student-teacher relationships to be critical to a sense of school belonging, while Saggers (2015) suggested that positive student-teacher relationships are "one of the most influential factors in successful inclusion" (p. 40). Thus, the importance of school climate and school connectedness has been supported by the current study and previous research. Furthermore, Tamara's comments relayed the active steps taken to improve school climate; "the more understanding the school did push out, the better the environment was", and the positive outcomes that she experienced through this indicated that school climate was something that could be actively addressed by the school.

8.6. Interagency Collaboration

The overall theme across the cases related to interagency collaboration was that **interagency collaboration between schools and outside school organisations and agencies was poor.** In fact, for the young adults and families in this research, there was no planned and supported ***transition*** according to the definition of the term (see Section 8.1). Rather, the process of transition involved school ending and the young adults and their families starting again to find and build post-school options with a distinct chasm between childhood and school-based services and adult services. Piper summed this up with "It was like a wave and shut the door to your face", while John's mother indicated that "They wouldn't know nor have any idea as to where he was going or what he was doing" after the final day of Year 12.

This finding was supported by research in both international and Australian studies. Roux (2015) stated that for most families in the United States the end of school is like "falling off a cliff", even though transition-focused education is mandated in the United States context (Mazzotti et al., 2014; Test, Fowler, et al., 2009). Similarly, Australian research also continues to support the chasm between school and outside school services. Cumming et al. (2020) described some parents as reporting positive levels of interagency collaboration while others reported negative experiences. Beamish (2012) found that secondary school teachers in Queensland schools rated interagency collaboration as one of the lowest TTP domains, indicating poor endorsement and implementation of interagency collaboration. These findings were despite the analysis conducted by O'Neill et al. (2016) who found that statements referring to interagency collaboration were located in four of the policy statements guiding education across the Australian states and territories. Thus, while the expectation is that Australian schools, including those in Queensland, will collaborate with community-based organisations and agencies, the actual practice of this is inconsistent at best.

The one positive area of interagency collaboration that was discussed by multiple participants was the collaboration between schools and TAFE so that students could gain TAFE qualifications during the final years of school. TAFE qualifications are specific to workplace expectations, and therefore receiving a TAFE qualification is likely to improve future opportunities for employment (Haschek et al., 2020). John completed a TAFE qualification in hospitality, while Tamara completed her qualification in early learning. For John particularly, having this qualification allowed him to move straight into employment in the hospitality industry after school. Although Tamara was looking for work, she was confident that she had the qualifications to do so because she had completed her school-based traineeship. Bruce’s mother also spoke about the school engaging closely with their local TAFE to provide students with qualifications in their area of interest. Other participants also discussed gaining TAFE qualifications, with Paul, Frank, and Helen all sharing that they had completed TAFE qualifications as part of their planned transition into employment, although this was done after school. Thus, the experiences of the young adults in this research supported the findings that young people on the autism spectrum value the work-related qualifications provided by TAFE and support the importance of interagency collaboration between schools and TAFE (Haschek et al., 2020). One negative area mentioned in this research regarding school-TAFE collaboration was that some schools provide only limited options for TAFE qualifications, thereby limiting the choices of qualifications that young students can gain. This was an area of difficulty for those young people on the spectrum who had strengths and interests outside the TAFE courses offered at their school or at the local TAFE.

Another key collaboration that is critical for young people on the autism spectrum is that between schools and universities. Three of the young adults interviewed, Eric, Anne, and Piper, were attending university, and, of these three, two shared negative experiences regarding the collaboration between school and university. Piper and Anne, and their mothers, described a significant lack of transition support between the school and university, with no sharing of documents, support strategies, or even a recognition of the autism diagnosis used in school.

Again, this finding was consistent with previous research conducted at Australian universities (Cai & Richdale, 2016; Thompson et al., 2019; Ward & Webster, 2018). The young adults and their families expressed real frustration with this lack of transition with Piper's mother stating that it "Felt like starting again. It didn't seem to matter that we knew … like that we had done this for years, it felt like we didn't know anything". These limited transition practices are significant given the experiences of young autistic adults with tertiary study (see Section 2.5.2), and the importance of appropriate supports being offered from the beginning of university attendance to ameliorate these outcomes (K. A. Anderson et al., 2018; Anderson et al., 2020; Cai & Richdale, 2016).

Other areas that were discussed in terms of negative collaborative experiences included collaboration between medical professionals and schools, collaboration between employment support agencies and schools, and the provision of information about post-school support agencies provided by schools. Again, each of these findings was consistent with findings from previous research (Cribb et al., 2019; Hatfield et al., 2017; Kuo et al., 2017). The noteworthy concern with these findings is that interagency collaboration relates specifically to the environmental factors that are present to support the effective transition from school to post-school options. That is, within the biopsychosocial model of disability, interagency collaboration relates to the environmental supports provided, as opposed to the personal characteristics of the autistic individual. From this perspective, these findings indicated that appropriate environmental supports are not provided to autistic youth as they prepare for, and transition to, post-school options. This supports the contemporary discussion that poor post-school QoL and self-determination for young autistic adults across domains are related not just specifically to the characteristics of the autistic individual but equally to the limited environmental supports provided during this critical transition period.

8.7. Inconsistent transition practices

The first of the presented key findings; transition practices across schools were inconsistent, was determined from the preceding information. Across all cases, the transition practices of the schools were very different. Schools had various strengths across the TTP domains, but none provided consistent practices across all

TTP domains. This finding replicates the findings of Beamish et al. (2012) and Cumming et al. (2020) that the implementation of transition practices is inconsistent across Queensland, and Australian, secondary schools.

8.8. Chapter Summary

The cross-case analysis of transition practices experienced by the young autistic adults was presented. All cases were considered in terms of the similarities and differences across cases within the five TTP domains: student-focused planning; student development; family involvement; program structures; and interagency collaboration. Although there were differences across the experience of each young adult, there were consistent themes identified to show that current transition planning processes are poor across all TTP domains. Student-focused planning was limited, with basic attendance at initial meetings consistent across cases. After this initial meeting, there was limited monitoring and evaluation of decisions made during this meeting. Concerningly, there were no experiences shared where the young people were taught component skills to support their engagement in student-focused planning, and the plans developed and implemented were often not based on the students' strengths and interests, goals, or aspirations. From this limited student-focused planning, student development across academic, life, social, emotional, and career or work-based skills was also limited. Assessment was not conducted to determine the strengths or needs of the individual across the recommended areas, so limited teaching of required skills, knowledge, and attitudes was addressed. Rather, the focus of student development was on academic skill development to progress through secondary school curriculum.

Family involvement in educational and transition-focused decisions was limited to sporadic attendance at meetings and attempts at communication to support the young people in their everyday interactions at school. There was no evidence of substantial family involvement in transition-focused education within the school, and no evidence of family empowerment or family preparation. Program characteristics, school climate, and the allocation of resources were the most common themes mentioned within the program structures domain. Program characteristics were described as academically focused and inflexible, while the examples of both positive and negative school climate experienced highlighted the critical role that this plays for autistic students and the impact that this has on both school-based and post-school QoL. The difficulties experienced with resource allocation, coupled with results across the TTP domains, emphasised the limitations resulting from limited policy and procedures, strategic planning, and program evaluation at both systemic and school-based levels. Although interagency collaboration between schools and TAFE was described in positive terms, effective interagency collaboration was not experienced across other sectors, including with medical and employment organisations. Finally, schools were not seen to be providing the information about, or access to, organisations and agencies that families needed to support effective school to post-school transition.

CHAPTER 9: ENABLERS OF EFFECTIVE TRANSITION PRACTICES

9.1. Chapter Overview

Chapter 9 addresses the final research question: ***What are possible enablers of the implementation of effective transition practices in secondary schools?*** To identify the key enablers, findings from the responses to the first two research questions were compared and analysed: ***How do young autistic adults perceive their current quality of life;*** and ***How and why have secondary school transition practices influenced the quality of life of young autistic adults?*** That is, the key themes identified through the cross-case analysis of the young autistic adults QoL (see Chapter 6) were compared to the key themes identified through the cross-case analysis of the transition practices experienced and the impact that they had (see Chapter 8). From this comparison and analysis, four key enablers of effective transition practices have been identified for secondary schools:

- ***Supporting high levels of family involvement***
- ***Focusing on the young person's strengths and interests***
- ***Supporting the emotional wellbeing of the young person, and***
- ***Providing a positive school climate.***

It is important to note that these four key enablers were not found to be the only important factors in transition. They were identified through the information shared by the nine young autistic adults and their parents, and through the analysis conducted by the researcher, as the four most important practices to the young autistic adults, and as those practices that are most likely to have the largest initial impact on the QoL of the young adults as they transition from school to post-school options. Importantly, none of the enablers identified can be viewed as a singular, solitary factor. Rather, all the domains within the Taxonomy for Transition Programming [TTP] (Kohler, 1996) and the Quality of Life [QoL] (Schalock & Verdugo, 2002) frameworks must be viewed as complex and interacting with one another to have an overall impact.

From this perspective, each key enabler was addressed by linking the information shared by the young autistic adults and their parents to the conceptual framework and to the interactions among all aspects of the framework. The findings of the research supported the conceptual framework presented (see Chapter 3). That is, the use of self-determination theory (SDT), and the mobilisation of a biopsychosocial model of disability, were shown to be an effective umbrella theory under which the wellbeing of young autistic adults could be determined, with both personal factors and environmental factors found to impact on the transition from school to post-school options. Significantly, it was shown that, for these young autistic adults, ***it was the complex interplay of the personal characteristics of the individual, and the responsiveness of the environmental factors to these personal characteristics, that resulted in adult QoL.*** Moreover, the findings of this research supported the use of both the TTP and the QoL frameworks for assessing the impact of secondary school transition practices on post-school QoL for young autistic adults. Thus, in assessing the impact of transition practices on post-school QoL, and in recommending key enablers for secondary schools, links to the conceptual framework, SDT, the biopsychosocial model of disability, the TTP framework, and the QoL framework were made.

9.2. Key Enablers

Significant research exists to show that school-based practices affect post-school QoL for young people with disabilities, including those with autism (Shogren et al., 2017). Test, Mazzotti, et al. (2009) identified 16 evidence-based school transition practices that supported post-school outcomes, including: inclusion in general education; self-determination, living, and social skills; and parental involvement, while Test, Fowler, et al. (2009) suggested instruction related to social and communication skills, self-advocacy skills, and parent involvement in transition planning and implementation as key supportive factors for positive post-school outcomes for young people with disabilities. In the Australian context, Winn and Hay (2009) discussed the various challenges relating to youth with disability transitioning from school to employment, and they recommended multiple practices, including providing all students with disabilities with appropriate instruction relating to academic, social, and interpersonal skills, and vocational instruction. Similarly, Pillay and Brownlow (2017) considered transition to employment for young people on the autism spectrum in the Australian context and identified four predictors of transition outcomes: supported workplace intervention; behavioural interventions; functional independence interventions; and family advocacy interventions. Finally, O'Neill et al. (2016) suggested that, given Australia's limited legislation regarding transition-focused education, it was "imperative that teachers ensure that students with disabilities have access to in-school experiences (predictors) and are taught transition skills needed via these practices" (p. 151).

This research has focused on identifying the key enablers for secondary schools to ensure that transition practices support a positive post-school QoL for young autistic adults. As was noted above, the enablers identified included: ***supporting high levels of family involvement; focusing on the young person's strengths and interests; supporting the emotional wellbeing of the young person; and providing a positive school climate.*** These enablers showed significant similarities to findings from previous research, with the differences most likely related to the sharing of young autistic adults' perceptions and the wider scope of viewing QoL across all domains. Importantly, these key enablers have been identified as strategies that can be more easily implemented within educational contexts by individual schools and teachers. That is, they can be implemented at a school level, rather than requiring systemic level changes such as policy change. Throughout this research, it was identified by the young adults and their parents that student-teacher relationships and interactions were critical. Thus, it was important to identify enablers that could be implemented through adjustments at the school and individual teacher levels.

9.3. Supporting Family Involvement

The first key enabler of effective transition practices in secondary schools was that of family involvement. Family involvement is a TTP framework domain and, as such, it is already recognised as a key supporting factor in effective transition-focused education (Kirby et al., 2020; Kohler et al., 2016; Wong et al., 2021). The findings of this research, however, identified a significant mismatch between the level of family involvement in secondary schools' transition planning and the level of family involvement in the transition from school to post-school options. The cross-case analysis findings in the family involvement domain were that families experienced poor levels of family involvement regarding transition-focused planning for their autistic adolescents (see Chapter 8). Although two of the parents reported high levels of involvement in their adolescents' school program, they also reported that this involvement was regarding decisions about the daily school program as opposed to planning for transition to post-school options. Significantly, even this level of involvement was minimal, with most – seven out of the nine – parents indicating that they had had little involvement in planning for their autistic adolescent's daily school program, or for the transition to post-school options.

Conversely, the level of involvement of families in the process of transition was significant, with both young adults and their parents referring often to the important role that families played in achieving and maintaining positive QoL across all domains (see Chapter 6). All young adults expressed the substantial levels of support offered across material, physical, and emotional wellbeing, regardless of whether the young adult lived in the family home or in her or his own home. All required supports for their emotional wellbeing, with the majority of support being provided by family, and mostly on a daily basis. Most young adults indicated that it was their parents who had taught them life skills, including financial and daily living skills. Most young adults also had significant family support in accessing and maintaining their post-school activities, regardless of whether they had moved from school to employment, postsecondary study, or accessing support services. Furthermore, those young adults who accessed supports from outside the family, such as NDIS funding and services, were able to do so because their family had set up and continued to manage this outside support.

Importantly, all the young adults perceived their level of self-determination as high; however, this was not related to the young adults not having or requiring family support, but instead to families providing targeted support that allowed the young adults to make decisions for themselves and to achieve their goals (see also Cribb et al., 2019; Mattys et al., 2018). For example, those young adults who lived in their own home did so with family support to help them to move in, and to maintain their own home and their personal wellbeing. A key aspect of the success of family involvement was the family's knowledge and understanding of the young adults:

their strengths, interests, and goals, and providing targeted support as required to work towards greater levels of self-determination (see also Taylor et al., 2019). Furthermore, the young adults acknowledged that being provided with supported autonomy, as opposed to independence, was critical to the development of their self-determination (Ryan & Deci, 2017).

The families of the young autistic adults provided the environmental supports needed across both spaces of transition: school and post-school options. Thus, because the families of the young autistic adults are the key implementers of transition practices, and because current family involvement practices in school-based transition practices are poor, ***secondary schools must improve their family involvement practices in transition-focused education***. Higher levels of family involvement have been shown to have multiple benefits, including, higher levels of parent efficacy (Goldman & Burke, 2019; Kurzrok et al., 2021) and parent self-determination (Dieleman et al., 2018); increased knowledge of services and agencies available post-school (Kuo et al., 2017; Snell-Rood et al., 2020); and improved positive forward planning (Chen et al., 2019; Walsh et al., 2021). Furthermore, increased family involvement has been suggested to have multiple benefits for the young person on the autism spectrum, including: the support for and the extension of student-focused planning and student development (Kohler & Field, 2003); increased relatedness between parents and adolescents; and increased autonomy in adolescents (Ryan & Deci, 2017). Finally, increased family involvement ensures that all stakeholders – schools, teachers, families, and the young people – have a shared understanding and are working towards the same goals and aspirations for the young adults.

9.4. Strengths and Interests

Focusing on the young people's strengths and interests as the main driver for transition-focused education was the second key enabler. Many individuals on the autism spectrum have one or more specific area of strengths and interests. Although strengths and interests are not defined as a core characteristic of autism, they are closely related to the core characteristic of rigid and repetitive behaviour, interests, or activities (American Psychiatric Association, 2013). Currently, this term has negative connotations attached to it, with these interests being viewed as problematic and as reducing the person's ability to function across the wide diversity of life contexts (Uljarevic et al., 2021). More contemporary research, however, recognised that these restricted interests are highly rewarding for individuals, and that they fulfil adaptive roles, including the facilitation of educational and vocational outcomes, and improving interpersonal relations and social participation (Grove et al., 2018; Wood, 2021). Furthermore, Grove et al. (2018) found that between 75% and 88% of autistic individuals have one or more restricted interests, and Meilleur et al. (2015) found that approximately two thirds of all individuals on the autism spectrum present with specific skill sets within their area of restricted interests. Thus, a large majority of individuals on the autism spectrum have at least one area of strength and interest that can be used to facilitate improved outcomes and wellbeing throughout the lifespan.

Perceptions shared by the young adults and their parents in this research supported these findings. Of the nine young adults, all identified a specific area of strength and interest, although, as expected, there was a large and diverse range of interests, including art, cooking, history, aircraft, weather, and physics. More importantly, the findings of this research indicated a significant link between the young persons' ability to engage in their strengths and interests and the overall QoL experienced across a range of domains. For many participants, opportunities to engage with their strengths and interests led to higher levels of emotional wellbeing, including resilience; higher levels of satisfaction with social participation; and significantly higher levels of self-determination, while those participants who were unable to engage in their strengths and interests, even for a short period of time, experienced significantly lower levels of wellbeing, social participation, and independence. Moreover, those participants who did experience poorer QoL used their strengths and interests to improve this situation and to regain positive QoL through engagement with their areas of strength and interest.

When comparing these QoL outcomes to the transition practices experienced by the young autistic adults during their schooling, and the connection to strengths and interests, these findings were further enhanced. Those young adults who shared that the school that they attended supported their strengths and interests and provided opportunities for these areas to be followed during the senior years of schooling reported higher levels of overall satisfaction with their school experience (see also Wood, 2021). Furthermore, all continued to experience positive subjective QoL as they transitioned from school to post-school options, and as they maintained their engagement with their strengths and interests, either through their jobs or as a personal activity. Those whose strengths and interests were not supported or encouraged by the school described poorer levels of wellbeing, including increased anxiety and depression, difficulties with academic achievement, and a poorer overall experience of schooling. For these young adults, all went on to describe how they improved their subjective QoL after school by "going back" to their strengths and interests, and by pursuing activities in these areas.

Given the poorer QoL outcomes reported for young people on the autism spectrum both during school and as they transition from school to post-school options, these findings are significant. ***The individual's strengths and interests can act as a key enabler of positive wellbeing and outcomes for autistic adolescents during school, while at the same time improving the chance of positive subjective QoL across domains post-school***. Focusing on the individual's strengths and interests was, however, not related directly to any one TTP domain. Rather, it encompassed important aspects of several domains. Student-focused planning becomes a critical path through which the individual's strengths and interests can be determined, and suitable options for promoting these strengths and interests can be identified. From there, flexibility in program structure will allow these options to be included in the school program, while student development within this area of strength and interest is more likely to result in positive outcomes (Wood, 2021). Finally, family involvement (see Section 9.2.1) will, in turn, provide schools with the additional supports to help to determine the young person's strengths and interests and to provide opportunities to support these strengths and interests. As many families reported already implementing these opportunities, schools could benefit immensely from working collaboratively with families on facilitating the young person's strengths and interests. Thus, through the integration of various TTP domains, support for the individual's strengths and interests can be achieved. In turn, higher levels of self-determination will be achieved through increased opportunities to meet the needs of autonomy, competence, and relatedness, all of which are suggested to be enhanced through a focus on the individual's strengths and interests (Grove et al., 2018; Ryan & Deci, 2017).

9.5. Supporting Emotional Wellbeing

The third key enabling factor for secondary schools was to include ***high levels of support for the emotional wellbeing of autistic adolescents*** during school and as they plan for their transition to post-school options. All the young adults shared the significant level of difficulty that they experienced with their emotional wellbeing, particularly their high levels of perceived anxiety. Interestingly, these high levels of anxiety were present regardless of the individual's subjective perceptions of QoL across other domains. That is, even when young adults experienced positive QoL across domains, they still described high levels of anxiety either generally or in specific situations. These findings are consistent throughout contemporary research, with a general understanding that people on the autism spectrum experience higher levels of perceived stress and anxiety than their nonautistic peers (Bishop-Fitzpatrick et al., 2018; Hirvikoski & Blomqvist, 2015).

Previous research findings also indicated that autistic individuals have fewer strategies for managing stress and anxiety in their everyday lives (Hirvikoski & Blomqvist, 2015), and fewer social supports to help them to manage their stress and anxiety (Bishop-Fitzpatrick et al., 2018). The findings of this study did not support these aspects of previous research. Rather, the young adults reported the use of multiple strategies to manage their perceived anxiety, including cognitive strategies, physical strategies, and professional support, thereby indicating that these young adults were able to learn and use strategies to manage high levels of anxiety. The young adults also reported that they received significant levels of support to help them to manage their anxiety, with the main support being provided by their family, followed closely by partners and close friends. This support, and the use of effective strategies, were perceived as mediating the effect of the anxiety, and thus as beneficial to the young adults' emotional wellbeing. While this family support for emotional wellbeing was present during the school years, most of the young adults and their parents reported an increased need for emotional support as the young adults took on the additional responsibilities associated with adulthood (see also Mattys et al., 2018).

Conversely, all the young adults and their parents shared their experience of limited emotional support being provided by schools, while also sharing the significant levels of anxiety that resulted from the sensory, social, and academic expectations present in secondary schools (see also Costley et al., 2021; Danker et al., 2019). None of the young adults referred to individualised support or the teaching of strategies to manage stress and/or anxiety, while four shared that the overall school climate and level of acceptance somewhat supported their emotional wellbeing during secondary school. One of those three young adults shared that the school had implemented a school-wide program aimed at improving social and emotional wellbeing. In this instance, the young adult indicated that the program had had a positive impact on the social climate of the school, which in turn provided a more positive emotional experience for her.

To summarise, the young autistic adults experienced perceived high levels of stress and anxiety as they transitioned to post-school options. The use of effective strategies and high levels of support moderated the negative outcomes experienced from these high levels of anxiety. Therefore, young autistic adults need to be equipped with effective strategies for promoting emotional wellbeing throughout their schooling to support their positive emotional wellbeing and QoL after school. As schools were described as providing limited support for emotional wellbeing, increased emotional supports is a key enabler of post-school QoL. The teaching of and support for emotional wellbeing are directly related to the TTP domain of student development (Kohler et al., 2016). However, given the complexity of emotional wellbeing, the connection to other TTP domains is also critical. For example, family involvement in schools was suggested by the young adults to be important for emotional wellbeing, with parents playing a key role in communicating school-based difficulties to school staff. Student-focused planning was also critical to emotional wellbeing in allowing the focus of the educational program to be on student strengths, thus increasing their sense of autonomy and competence, and their overall wellbeing.

Therefore, increased emotional supports should be offered across all three basic psychological needs – autonomy, competence, and relatedness – and as such will link to important factors from across the TTP framework. The experience of autonomy for adolescents on the autism spectrum has been strongly linked with increased levels of self-determination (Shogren et al., 2017), and with higher levels of self-determination being related to emotional wellbeing (Ryan & Deci, 2017). The importance of experiencing competence in schooling contexts has also been closely linked to emotional wellbeing (see Section 9.2.2), while significant research has linked emotional wellbeing to the experience of relatedness (Adams et al., 2016; Costley et al., 2021; Mazurek, 2014). Furthermore, both personal and environmental emotional supports should be provided. Teaching students on the autism spectrum individual strategies to address their own specific anxieties is supportive of their emotional wellbeing (Hare et al., 2016; Johnco & Storch, 2015). Concurrently, providing environmental supports to enhance autonomy, competence, and relatedness will also improve emotional wellbeing (Ryan & Deci, 2017). These environmental supports require school-wide approaches to improve the experience of inclusion, acceptance, and feeling valued in the context of school, and are closely related to the final key enabler of providing a positive school climate (Roberts & Webster, 2020).

9.6. Positive School Climate

The final key enabler, ***providing a positive school climate***, refers to the social characteristics of a school in relation to the interactions between students and staff/teachers, and the values and norms of the school. Thus, the construct of school climate is complex and multi-dimensional, and "has been described as the unwritten personality and atmosphere of a school, including its norms, values, and expectations" (Maxwell et al., 2017, p. 2). School climate has been recognised as a leading predictor of students' academic engagement and achievement, motivation, and wellbeing (Maxwell et al., 2017; Roberts & Webster, 2020). School climate is identified as a factor within the program structures domain in the TTP framework, indicating that school climate is already recognised as a key enabler of effective transition-focused education (Kohler & Field, 2003).

A critical aspect of school climate is the psychosocial school atmosphere or the social interactions between students and school staff and peers (Maxwell et al., 2017). This construct is often referred to as school connectedness or school belonging, and refers to how valued, accepted, and included individual students feels in their school community. Research conducted by Saggers (2015) identified relationships with teachers and social support and friendships as key enabling factors in a positive school experience for students on the autism spectrum, while Carrington et al. (2021) and Shochet et al. (2021) both summarised the importance of a positive sense of school connectedness for supporting positive wellbeing throughout school, and identified school connectedness as one of the strongest predictors of current and future wellbeing for students on the autism spectrum.

School climate and school connectedness featured heavily in the interviews with all the young adults and their parents. All the participants referred to the importance of positive relationships with school staff and peers, and, while all the young adults identified school as a stressful period of their life, those who experienced a sense of being valued, accepted, and included in their school community described more positive levels of wellbeing and engagement at school. Furthermore, those who identified a positive school climate and increased levels of connectedness to school staff and peers during school also identified the transition to post-school options as being more successful.

The relationship between autistic students and school staff was based on several key features: understanding, acceptance, high expectations, and flexibility (see also Roberts & Webster, 2020). An understanding of autism was suggested by the young adults to be an important characteristic of school staff; however, this was because the young adults saw an understanding of autism as supporting the school staff in understanding them as individuals. Thus, it was the understanding of who they were, their strengths and interests, as well as their struggles and needs, that was important to the young adults. It was from this understanding of them as individuals that students were able to experience acceptance, and that teachers were able to hold high expectations and to adjust the school program to suit their needs and to encourage their success. Thus, school staff ***getting to know their students as individuals*** was identified as a critical aspect of a positive school climate.

Friendships and acceptance by peers were also identified as critical to the experience of school connectedness. All the young adults in this research shared the difficulties that they experienced in initiating, maintaining, and managing friendships at school. Yet young autistic adults have consistently shared the importance of these social relationships in their achievement, motivation, and wellbeing during school (Autism Spectrum Australia [ASPECT], 2013; Saggers, 2015). Furthermore, the experiences shared by the young adults and their parents highlighted the connection between the level of understanding and acceptance by school staff and their acceptance by peers, with positive staff acceptance being strongly associated with positive peer acceptance (Grutter & Meyer, 2014). Positive relationships with school staff, as described by the young autistic adults, also impacted on the level of bullying experienced by the young adults. Although some bullying did occur for most of the young adults during their school years, those who described a positive school climate also described the school staff's quick and effective response to address the bullying. Conversely, those young adults who described poorer relationships with school staff described ineffective responses to instances of bullying (see also Adams et al., 2016).

Thus, the connection among positive school climate, a sense of school connectedness and belonging, and positive student wellbeing was indicated through the experiences shared by the young autistic adults and their parents. This positive wellbeing experienced during secondary school was, in turn, associated with more positive wellbeing across QoL domains as the young people transitioned from school to post-school options. It was also strongly associated with meeting their basic needs of autonomy, competence, and relatedness in the school context, and indicated the importance of meeting these needs during school years to support their self-determination in adulthood (Ryan & Deci, 2017). These findings therefore supported Roberts and Webster's (2020) assertion that "educational and personal outcomes for students on the autism spectrum are optimal when schools adopt a whole-school approach" (p. 11) to supporting students, regardless of their personal characteristics.

9.7. Chapter Summary

Chapter 9 provided the response to Research Question 3: ***What are possible enablers of the implementation of effective transition practices in secondary schools?*** To respond to this question, the cross-case analyses from Chapter 5 and Chapter 6 were analysed, and key similarities and differences in terms of the young adults' experiences of secondary schooling practices and the impact that these experiences had on their current QoL were considered. From this analysis, the key enablers of the implementation of effective transition practices in secondary schools, as identified by the young autistic adults, were presented.

The four key enablers identified by the young adults and outlined in Chapter 9 were: ***supporting high levels of family involvement; focusing on the young person's strengths and interests; supporting the emotional wellbeing of the young person; and providing a positive school climate.*** Although each of these enablers was discussed individually, the complex interactions among all four key enablers, and their links to the TTP and QoL framework, were also highlighted. As such, these four enablers were not suggested to be the only transition-focused practices that are important in supporting the school to post-school transition of young autistic adults. Rather, they are suggested to be four key focus points that individual schools and school staff can use to begin their journey towards the implementation of effective transition-focused education for autistic students in secondary schools.

CHAPTER 10: BRINGING IT ALL TOGETHER

10.1. Chapter Overview

This chapter presents the final research findings of the study and suggests how these research findings may be used to support young autistic adults as they transition from school to post-school options. The findings from, and implications of, the three research questions are addressed, with a discussion of what this means for quality of life (QoL) for young adults on the autism spectrum, and how secondary school practices can support an effective and positive transition to post-school options. A strengths-based focus remains throughout the chapter, from the young adults', families', and schools' perspectives, so that the discussion continues to be about what can be done to support positive QoL, as opposed to what cannot be, or is not being, done, and what results in a negative QoL.

The remainder of the chapter considers how the study contributes to knowledge, and how this new knowledge could be used by various stakeholders. It also offers suggestions for moving forward with future research. The contribution to knowledge is addressed in theoretical, conceptual, methodological, policy, and practical terms. These contributions are considered for a range of stakeholders: young autistic adults; their families, teachers, and schools; and educational and community organisations. The strengths and limitations of the research are explored, and the researcher suggests possible directions for future research. Finally, the researcher's personal note is revisited, and the thesis ends with a message from the young autistic adults who participated in the research.

This final chapter is considered within the conceptual framework presented in Chapter 3. Thus, the productive combination of self-determination theory (SDT) (Ryan & Deci, 2000), a biopsychosocial model of disability (International Classification of Functioning Disability and Health [ICF], 2002), and a strengths-based view of autism (Autism Spectrum Australia, n.d.), was used to establish how the Taxonomy for Transition Practices (TTP) framework (Kohler, 1996) could be used to support positive QoL (Schalock & Verdugo, 2002) for young autistic adults as they transitioned from school to post-school options.

10.2. Findings Arising from the Research Questions

The current research study investigated three research questions under the overarching question: ***How do young autistic adults perceive the interaction between secondary school practices and post-school quality of life?***

1. ***How do young autistic adults perceive their current quality of life?***
2. ***How and why have secondary school transition practices influenced the quality of life of young autistic adults?***
3. ***What are possible enablers of the implementation of effective transition practices in secondary schools?***

Qualitative case study research was undertaken with nine young autistic adults and their parents to elicit their perceptions regarding the above research questions. From this data collection and analysis, the following findings were shared.

10.2.1. Research Question 1: Young Autistic Adults' Quality of Life

Overall, the QoL of the young adults was perceived to be positive. Although there were differences in the perceptions of the young adults across the eight QoL domains, both individual cases and cross-case analysis showed primarily positive experiences. Furthermore, the perceptions of the young adults' parents supported this overall positive perception of QoL. The young adults acknowledged that, while they had experienced challenges during the transition from school to post-school life, with high levels of family support, and high levels of resilience, all were working towards maintaining and improving their QoL across all domains: wellbeing; social participation; and independence.

Within the QoL domains, wellbeing considered the material, physical, and emotional wellbeing of the individual. For the young adults in this study, consideration of wellbeing was taken from the perspective of SDT. That is, did the individual participants experience autonomy, competence, and relatedness within their material, physical, and emotional wellbeing (Ryan & Deci, 2017)? The findings indicated that most of the young adults did experience autonomy within the wellbeing domain. The young adults actively made decisions regarding their living situation, employment, and financial status, and they developed and implemented strategies to support their positive physical and mental health. For the young adults, however, these decisions were made and implemented with the support of their family. The level of competence experienced by the young adults across various life skills determined how much support they required from their families to maintain this level of autonomy. Importantly, all families actively supported the young adults to develop further the autonomy and competence required to move as close to independence as possible (see also Cribb et al., 2019; Mattys et al., 2018; Taylor et al., 2019).

Throughout the interviews, all participants and their parents described ***perceived high levels of stress and anxiety*** experienced by the young autistic adults. Although the environments and situations that caused these high anxiety levels, and the ways in which high levels of anxiety were expressed, also varied, high anxiety was a crucial aspect of the perceived emotional wellbeing of all participants. The description of each participant's QoL referenced both high anxiety and the strategies that they developed, or the supports that they required, to overcome this anxiety. Smith et al. (2019) suggested that anxiety is a significant area of challenge for people on the autism spectrum, and the participants in this study supported this finding. However, a critical aspect of the young adults' emotional wellbeing and anxiety was the perceived level of support provided to them by family and close friends. All the young adults, and their parents, described the supports provided and how this high level of support mediated the impact of anxiety on QoL for the young adults (see also Bishop-Fitzpatrick et al., 2018). Within this domain, the importance of relatedness, or the perception of "experiencing others as responsive and sensitive and being able to be responsive and sensitive to them" (Ryan & Deci, 2017, p. 93), for both wellbeing and social participation could be seen.

The QoL domain of social participation considered interpersonal relations and social participation in the community. Interpersonal relations refers to the relationships an individual has with family and friends, the types of activities in which the individual participates with family and friends, and the amount and type of support that the individual receives (Schalock & Verdugo, 2002). Most participants expressed that they had positive relationships with their family, and all acknowledged the high levels of support provided by their family to encourage social participation (Cribb et al., 2019; Mattys et al., 2018). Despite small difficulties described by the young adults and their parents, all participants experienced a considerable number of their positive interpersonal relationships through their families, as the young adults described close relationships with their parents, siblings, and extended family, and talked about the various activities in which they participated with their families.

Friendships were also important; however, the participants emphasised that a small number of close friends was their preference. The area of friendships was one where the young autistic adults and their parents shared different expectations in terms of QoL. While parents were concerned about the small number of friends with whom their young adult children engaged (see also Mattys et al., 2018), the young adults shared that this small number of friends was intentional and satisfactory. The descriptions by the participants in this research supported the findings of Smith et al. (2019) that the assumption that having more friends and spending more time with friends results in a higher QoL does not necessarily represent how autistic individuals experience friendships. Instead, the autistic adults in this research described how they prefer to spend limited time with good friends who understand and accept them, while also ensuring that they have time to be by themselves (Cribb et al., 2019; Crompton et al., 2020; Mattys et al., 2018).

Although some young adults in this study indicated significant difficulties in developing and maintaining friendships, and in participating in community activities, others shared the strategies that they had developed to be able to make and keep friendships. Descriptions of a more structured, prescribed way of interacting with nonautistic people, and of engaging in everyday conversations, were again similar to descriptions shared by individuals on the autism spectrum in previous research (Bradley et al., 2021). Many of the young adults also described the negative impact that interpersonal relationships and social participation with nonautistic people can have on emotional wellbeing over time (Cage & Troxell-Whitman, 2019; Morrison et al., 2020). Hence, there was a constant tension between the need to establish a sense of relatedness with others and at the same time to navigate the different experience of relationships for autistic individuals. An understanding of different individual experiences of friendship and of the strategies used to mediate these differences was critical to maintaining both interpersonal relations and emotional wellbeing for young autistic adults.

There were two themes identified in the domain of personal development. These were the ***importance of strengths and interests*** and ***high levels of family support in personal development***. For all young adults, the importance of strengths and interests came through as a key indicator to facilitate continued personal development both in the school context and when the young person had transitioned to post-school options: employment; postsecondary study; and community engagement. Regardless of the post-school QoL domains, the young autistic adults continued to follow their own path towards personal development when it was related to, or supported, their strengths and interests. Importantly, this research showed that young autistic adults experienced high levels of intrinsic motivation, autonomy, competence, relatedness, and wellbeing when engaging in activities related to their strengths and interests (Ryan & Deci, 2017).

Self-determination was the final domain within the QoL framework that was investigated in this study. It is important to acknowledge here that self-determination is not a single construct, and, as such, every other QoL domain influences the level of self-determination experienced by people, including the young autistic adults who participated in this study (Ryan & Deci, 2017). The two themes identified in this study relating to self-determination were that the young adults experienced ***high levels of perceived self-determination***, and that the high levels of perceived self-determination were supported by ***high levels of family support for self-determination***. Autonomy and personal control were not perceived by the young adults, or by their parents, as functioning completely independently of their families and support structures. Instead, high levels of self-determination, autonomy, and personal control were seen to exist because of the support received through their families (see also Taylor et al., 2019). The young adults in this study acknowledged that their families understood their strengths and needs and worked closely with them to encourage and support their autonomy, competence, and relatedness, thus supporting their self-determination in adult life.

10.2.2. Research Question 2: Secondary School Transition Practices

Throughout the interviews conducted with the young autistic adults, an overall negative perception about current secondary school transition practices was shared. The young adults felt that the current secondary school practices did not support their transition to post-school options across most domains. This resulted in most young adults experiencing some challenges in their QoL as they transitioned to various post-school options. Specifically, all the young adults on the autism spectrum experienced challenges in the emotional wellbeing QoL domain. Furthermore, the young adults linked these emotional challenges back to the limited social and emotional supports and strategies provided during secondary school; a limited focus on the strengths and interests of the young people; and poor school climate.

Overall, the young adults and their parents perceived the transition planning and practices of secondary schools as poor. The current transition planning process was seen as little more than "subject selection" and did not meet the requirements of student-focused planning, especially in the areas of student participation, and building transition plans based on individual students' strengths and needs. This resulted in many autistic adolescents experiencing a disconnect between their personal post-school goals and their goals achieved through secondary school. Student development was also seen as failing to teach the students the specific skills required to transition to post-school and to pursue successful tertiary studies, employment opportunities, and independent living (Duncan et al., 2022; Ghanouni et al., 2021). Thus, many of the young adults experienced a gap between skill level and adult expectations, with families and adult support services required to teach these skills to maintain post-school progress. Interagency collaboration, particularly between secondary schools and adult services and organisations, was considered ineffective by all the young adults and their parents (see also Howlin, 2021). For the young adults, this led to a gap between school and post-school where the young adults and their families were required to "start again", finding and implementing the required supports to ensure a positive QoL (see also Cheak-Zamora et al., 2015; Cribb et al., 2019).

The level of family involvement in school-based transition practices was very low, especially when compared to the level of family involvement in the planning and implementation of school to post-school transitions outside the transition planning initiated by the school. While parents were actively planning and implementing the transition to post-school options, this was done with little involvement or knowledge from the schools (Hatfield et al., 2018; Hatfield et al., 2017). Thus, greater levels of collaboration between schools and the young people and their families are required.

Finally, these poor school-based transition practices were underpinned by a lack of legislation and policy guidelines in relation to the Queensland, and Australian, educational context. This lack of guideline support, in turn, hampered attempted transition practices (Cumming et al., 2020; O'Neill et al., 2016). Even when schools and families attempt to implement effective practices, they are hindered by issues related to resourcing, autism specific resources, and interagency collaboration. As a result of these poor transition practices, the impetus for successful transition from school to post-school options was the responsibility of the young adults and their families. This finding was supported by Cribb et al. (2019) and Hatfield et al. (2018), who also found that the onus is on the family to provide the necessary supports for an effective transition from school to post-school options.

10.2.3. Research Question 3: Key Enablers of Effective Transition Practices

What were the possible enablers of the implementation of effective transition practices in secondary schools? The four key enablers for the young autistic adults and their families in this research study were found to be: supporting high levels of family involvement; focusing on the young person's strengths and interests; supporting the emotional wellbeing of the young person; and providing a positive school climate**.** Significant levels of family involvement were found to be a critical element for schools in supporting positive QoL for young people on the autism spectrum. The families of the young adults in this study undertook the main role of supporting the young person as they transitioned to post-school options. Furthermore, the families recognised the need for continued and changing support at each stage of the transition period and well into adulthood (see also Mattys et al., 2018). While it may not be feasible for schools to provide support to young adults after they have transitioned out of school, these findings highlighted the important role that schools could play in helping to prepare and empower families for the years of support and advocacy ahead of them (Cribb et al., 2019; Sosnowy et al., 2018).

The key QoL domain where the young autistic adults reported difficulties, regardless of outcomes in other QoL domains, was emotional wellbeing. Autistic individuals have been found to experience high levels of co-occurring anxiety (Bishop-Fitzpatrick et al., 2018; Spain et al., 2018), and these findings were replicated for the young adults in this study. Furthermore, the young adults and their parents identified specific aspects of school practices that either exacerbated or reduced the experience of anxiety during this critical period. Therefore, strategies to support the emotional wellbeing of young adults as they plan for and transition to post-school options were identified as a critical enabler of enhancing post-school QoL. These strategies included: ***supporting the emotional wellbeing of the students*** (see also Danker et al., 2016); ***focusing on the students' strengths and interests*** (see also Wood, 2021); and ***ensuring a positive school climate*** (see also Shochet et al., 2021).

10.3. Contributions to Knowledge

This study has made significant contributions to knowledge across the following areas: theoretical, conceptual, methodological, policy, and practice. These contributions to knowledge can be used to inform further a range of people involved in the transition from school to post-school options for young people on the autism spectrum. First and foremost, young autistic adults can take the knowledge shared by nine of their autistic peers and use the information to support their own thinking and planning about the transition to post-school options. Significantly, the study offers positivity and hope for young people on the autism spectrum, that they can achieve their goals and aspirations as adults (Cribb et al., 2019). Likewise, parents of adolescents or young adults on the autism spectrum may also find similarities between the experiences described in this study and their own, informing strategies that they can use to support further their autistic adolescent and young adult children, both during secondary school and as they transition to post-school options.

In the education context, policymakers can consider the importance of implementing appropriate transition-focused educational policy to ensure that schools are provided with the strategic planning, policies, and procedures to implement effective transition practices (Cumming et al., 2020; O'Neill et al., 2016). School staff, including administrators, teachers, and support staff, can also learn from the experiences shared in this research by making connections with the experiences of the young people with whom they are working. Most importantly, schools may like to consider the four identified enablers of effective transition and assess how these could be further incorporated into their current practices. Finally, organisations and agencies involved in providing services and supports for autistic adults may also consider the suggestions provided in this research regarding how they support young autistic adults and their families as they transition to post-school options.

10.3.1. Theoretical and Conceptual Knowledge

The use of SDT (Ryan & Deci, 2000) to underpin this research provided a conceptual framework through which the research could be considered. The benefit provided to the researcher was in measuring QoL through the three basic psychological needs for individual wellbeing: autonomy, competence, and relatedness. To use this theory with people on the autism spectrum, a more nuanced understanding of the needs of autonomy, competence, and relatedness was required to understand accurately the subjective experiences of QoL and transition practices from the perspectives of the young autistic adults. It was important that the researcher could step back from the more common perception of autonomy that exists in Australian society, whereby autonomy is based on the severing of the relationships and interdependence between families and their adult children. Instead, a more nuanced understanding of autonomy as "the need of individuals to experience self-endorsement and ownership of their actions and to be self-regulating" (Ryan & Deci, 2017, p. 97), and that this can indeed occur within the interdependent relationship between families and adult children, is critical. In this way, SDT was shown to be appropriate for considering autistic individuals' wellbeing and QoL; they can experience autonomy, competence, and relatedness, regardless of the supports required to ensure that this occurs (Kim, 2019; White et al., 2018).

Furthermore, the findings of this research contributed to the assumptions underpinning the universality of SDT. That is, SDT is an appropriate construct of wellbeing that is applicable to all people, including people who experience disability, and specifically people on the autism spectrum.

The conceptual framework used throughout the research highlighted the complex connections among SDT, autism and its characteristics, the biopsychosocial model of disability, transition practices, and QoL. The key point highlighted through this conceptual framework was the clear connection among the individuals with autism, their personal characteristics, and the environments in which they live. Moving away from the medical model of disability, where the challenges experienced by the individual are seen as the result of that person's characteristics, this conceptual framework highlighted the key role that the provision of an appropriate environment plays in the overall experience of the individual. That is, disability related to a diagnosis of autism is experienced owing to a misfit between the individual's characteristics and an environment that fails to consider or support the basic psychological needs of the individual. Therefore, by changing the environment to be more supportive of these basic psychological needs during the transition period, positive QoL can be supported (Hagiwara et al., 2020).

10.3.2. Methodological Knowledge

Methodological contributions to knowledge from this study fell in two key areas: the sharing of the young autistic adults' subjective perceptions about their QoL and the transition practices experienced; and the role of universal design in the development and implementation of the research. Much of the research to date has focused on assessing the QoL of young autistic adults through quantitative measures. These measures compare the QoL of young autistic adults with pre-determined objectives such as being employed and independent living, and do not consider the subjective experience of the young adult. Objective measures have typically resulted in young autistic adults being portrayed as having a poor QoL (Bishop-Fitzpatrick et al., 2016). This research supported more contemporary research findings; that is, the measurement of the subjective experience of QoL, as rated by young autistic adults, portrays a more positive QoL outlook for autistic individuals. This positive perception of QoL supports the move away from a deficit view of autism, provides positive expectations for young people on the autism spectrum and their families, and allows schools to see the positive impact that they can have on the life-time outcomes of autistic students.

To share this important voice of young autistic adults through research, a universal design approach to research design and implementation was undertaken. Engaging in research with autistic individuals has been considered difficult owing to their differences in social communication and behaviour, and the increased risk of their heightened anxiety. Universal design strategies used throughout this research included: providing information sheets, consent forms, and the interview questions in diverse formats; the co-construction of information sheets; flexibility in the timing and location of interviews; offering alternative interview formats such as face-to-face, online, and written; the use of visual supports throughout interviews; and working closely with families of the young people to ensure that the communication preferences of the autistic individuals were considered (see also Tesfaye et al., 2019). The use of these strategies encouraged and supported the participation of a wide range of participants, including those who may have typically been excluded from research. Importantly, the universal design approach to research methodology challenged the view that consistent participation approaches must be used to yield valued findings in qualitative research. Rather, universal design approaches in research support the sharing of multiple voices, thus challenging the negative views of disability and autism. From this, the wider community can come to see autistic people as they see themselves: an example of the broad and positive diversity that exists within the human population.

10.3.3. Policy Knowledge

The importance of implementing and supporting appropriate transition-focused policy in Queensland, and Australian, education contexts was highlighted within this research. The perceptions shared by the young autistic adults and their families were that limited policy support for schools impacted negatively on the school’s ability to meet the needs of the young adults or their families during the transition from school to post-school options. Two key areas were highlighted. All the young adults and their families reported that there were no specific transition plans developed, or used, in secondary schools; and that the SET planning process was not sufficient for planning and implementing effective transition-focused education for students on the autism spectrum. While acknowledging that the key goal of education in Australia is to ensure that all young people have the skills, knowledge, and attitudes to navigate adulthood successfully (Education Council, 2019), specific policy implementation is required to support schools in their endeavours. Unlike schools in the United States, which have specific policies for implementing transition-focused education (Mazzotti et al., 2014), Australian states and territories do not have similar policies (O'Neill et al., 2016). While most research supporting the use of transition-focused policy to support post-school outcomes for people with disability has come from the United States, Australian education leaders involved in policy development can use this research as support for the importance and relevance of transition-focused educational policy in the Australian and Queensland education systems.

The second area in which this study can support policy development is that of training for autism awareness for all teachers working in Australian schools. All the young adults and their families emphasised that individual teachers' awareness and understanding of autism had a significant impact on the experience of schooling, the level of transition-focused education provided, and post-school QoL. This study can be used as evidence to support policy development for ongoing education about autism for school staff, including all teaching and leadership staff. Policy development may provide the impetus needed for initial teacher education programs, and professional development programs for staff, to include autism specific knowledge, thus supporting both teachers and autistic students (Beamish et al., 2021). Throughout this research, some individual schools and their staff members were working towards implementing transition-focused strategies; however, the lack of appropriate policy reduced the effectiveness of this individual effort. Policy development and implementation across these two areas will support schools in accessing appropriate resources, particularly staff with autism specific knowledge who can work closely with students on the autism spectrum to develop effective transition-focused educational plans.

10.3.4. Practice Knowledge

Beamish et al. (2012) provided evidence that Queensland school staff view the TTP domains as appropriate for transition-focused education in Queensland schools.

The findings of this research added some support to the use of the TTP as a possible framework for use in Queensland secondary schools, although further research is needed. As found by Beamish et al. (2012), while the TTP framework is appropriate, the level of implementation of these practices is low. From the perspective of the young autistic adults and their families, most schools have areas of strength and areas of need in terms of transition-focused education for students on the autism spectrum across the TTP domains. The areas of need in transition-focused planning and education were found across each of the five practices.

Within the domain of ***student-focused planning,*** the recommended strategies – high levels of student involvement in transition-focused planning; and teaching and preparing students to be involved in transition-focused planning – were key practices that needed to be implemented with greater fidelity. A critical area of need was focusing on the strengths and interests of the young people. It was found through this research that student-focused planning was limited to subject selection for senior secondary education. A stronger focus on the strengths and interests of the young people themselves, and on their goals for using their strengths and interests post-school, would support the implementation of more effective student-focused planning. Furthermore, a focus on strengths and interests is likely to encourage further the active engagement and self-determination of the young people in making decisions about their education and transition.

It was also found that schools placed significant emphasis on academic achievement, to the detriment of social and emotional, occupational, and life skills, thus impacting negatively on overall ***student development***. A critical area of need for young adults on the autism spectrum is support for positive emotional wellbeing. Against that backdrop, this study supports the development and implementation of effective social and emotional practices in all school environments. It can also be suggested that the use of strengths and interests (see Section 8.2) could be a strong determinant of individual student development needs.

Family involvement was presented by the young adults and their families as a significant domain in this research study. Families were the key stakeholder in the young adults' transition, and as such, schools and families would benefit from a more collaborative working relationship for developing and implementing transition-focused education (see also Hatfield et al., 2018; Hatfield et al., 2017). Teachers and schools would receive significant benefits through incorporating the knowledge and understanding that families have regarding their adolescent child on the autism spectrum: their strengths and interests; their goals for the future; and the skills needed to work towards these goals. In turn, school collaboration could provide families with information and training to empower and prepare them further for their young adults' transition journey. Specifically, schools should ensure that families play a key role in school-based transition-focused decisions (Hodgetts et al., 2018); assisting families in the development of transition activities, skills, knowledges, and attitudes (Hatfield et al., 2017); and locating and accessing initial adult support services as the young person moves out of school (Kuo et al., 2017; Snell-Rood et al., 2020). Through the practice of family involvement, schools will significantly improve the transition from school to post-school for young autistic adults.

Practices within the TTP domain of ***program structures*** relate primarily to providing educational policies and procedures. In turn, these policies support the flexible resource development and allocation and the structures needed within programs to support the above domains: student-focused planning; student development; and family involvement. The domain of program structures is primarily focused on providing appropriately supportive environments for young people on the autism spectrum. Practices that will be supported by policy development, but that can be initiated by individual schools, relate to school climate. A positive school climate, where students on the autism spectrum are respected and valued, and experience positive relationships with both teachers and peers, has been highlighted in this research as a key factor in overall student wellbeing, and as having a significant influence on post-school QoL (see also Shochet et al., 2021). School climate, while influenced by overall educational policy, can be improved by everyday practices and attitudes at a school level.

As with program structures, ***interagency collaboration*** provides key environmental supports for young autistic adults as they transition from school to post-school options. Some examples of effective interagency collaboration, such as adolescents being able to complete Technical and Further Education (TAFE) qualifications while still at school, were shared. However, the young adults and their families primarily reported a significant gap between school-based and post-school resources and supports. Although addressing interagency collaboration requires involvement and policy development across multiple agencies, the young adults and their parents suggested that schools acting as “information hubs” for parents of students on the spectrum would provide substantial support for the families. That is, to have staff members in the school environment who are knowledgeable about post-school services, and for them to share this information with families during transition planning, would be beneficial to families as the young person transitions out of school (see also Snell-Rood et al., 2020).

10.4. Strengths and Limitations of the Research

The strengths-based approach used in this research allowed a focus on what the young autistic adults had achieved and could do, rather than a focus on the differences and difficulties experienced. The same strengths-based approach was also applied to the parents and families of the young adults with an emphasis on what they had done and continued to do to support the young person, as opposed to the difficulties that they experienced in the provision of this support. Furthermore, this strengths-based focus was applied to the suggested enablers of the implementation of effective transition practices that schools can begin to implement without significant policy change, for example – engaging more with parents/families; focusing on student strengths and interests; and providing a positive school climate. Although the importance of supportive policy and practice is recognised, these enablers provide individual schools and teachers with immediate actions that can be implemented.

The qualitative research design also presented as a strength. This research design allowed a focus on the subjective measurement of QoL and transition practices for the young autistic adults. Thus, no comparison was made between autistic and nonautistic individuals, and the focus was on understanding what was important from the young adults’ perspective. Multiple case study design (Merriam, 1998; Stake, 2005) provided a diversity of participants and contexts, allowing the identification of similarities and differences within this diversity. In this way, generalisations across cases could be made, while highlighting the uniqueness of each case. Rich, thick descriptions provided about the experiences of the young adults supports readers to make generalisations to their own context, thus taking and applying relevant information as they see fit (Miles et al., 2014).

A final strength in this research was the use of parent voice to support and extend the views of the young autistic adults. High levels of consistency between the views of the young adults and their parents can be viewed as a strength in terms of the research conducted and the triangulation of data, but also showed strength in the family unit as they navigated the transition from school to post-school options. Supportive parent voice reinforced findings that show that young autistic people can have high levels of experiential self-awareness and are able to share their understandings and perceptions of their QoL, the educational and transition practices in schools, and how the two interact (see also Hong et al., 2016).

Limitations within the study also need to be acknowledged. The young adults in the present study were not representative of all young autistic adults. The experiences described and analysed in this research were specific to the individuals interviewed, and transferability of findings cannot automatically be applied to all young autistic adults (Merriam & Tisdell, 2016). Although an attempt was made to ensure a high level of diversity among the young autistic adults, the participants were not representative of young adults with autism who do not use verbal language to communicate or who experience extreme levels of anxiety when communicating with unfamiliar people. While this was not intentional, I concede that a broader range of universal design methodologies may have been needed to support the participation of these young adults. Additionally, while a potential limitation could be not having a formal diagnosis of autism, this was a recognition of the broad diversity of autism and an acknowledgement that not having a diagnosis of autism does not preclude the experience of autism.

Finally, the sole reliance on interview data at one point in time is a noted limitation of the research. Case study research typically relies on multiple data collection forms, including interviews, observations, and document analysis, and occurs over a longer period of time (Merriam & Tisdell, 2016). For this research, the use of parent interviews provided triangulation of the data provided by the young autistic adults; however, further triangulation methods would have strengthened the research findings. Additionally, the perceptions of teachers and post-school organisations and agencies would have also provided a variety of views and more in-depth findings. It is recognised that perspectives from multiple stakeholders are needed to support educational planning. The transition from school to post-school options is a “cross-disciplinary and cross-organisational” (Snell-Rood et al., 2020, p. 1165) process, and as such requires the compilation of research from multiple sources. This research addressed just one small, but critical, aspect: the perceptions of young autistic adults and their families.

10.5. Future Directions

The outcomes of this research support several directions for future research by revealing that the young autistic adults experienced an overall positive QoL in young adulthood. The QoL domain of emotional wellbeing, however, was one area where all the young adults described significant difficulties. Further research into the experience of emotional wellbeing and heightened anxiety is recommended. In particular, research into appropriate supports that could be provided at this critical life transition to reduce the level of anxiety experienced, or to teach young adults with autism appropriate strategies to minimise and manage their heightened levels of anxiety, is critical. Alongside this, further investigation into the high levels of resilience demonstrated by the young adults in this research would continue the strengths-based approach taken throughout the research. Resilience in autism is an under-recognised and under-researched phenomenon (Montgomery et al., 2008; Muniandy et al., 2021). Yet, as demonstrated by the young adults in this research, high levels of resilience support the young people as they navigate the difficulties encountered throughout the transition from school to post-school, and as they navigate the expectations of adulthood in a primarily nonautistic society. Research that considers how resilience is developed in childhood and adolescence; how families and schools can support the development of resilience in autistic individuals; and how resilience can be fostered in adulthood will provide significant benefit to people on the autism spectrum and to those who support them.

This research also revealed that significant levels of family support were provided to the young autistic adults as they transitioned from school to post-school options. Concurrently, the research highlighted that families of young autistic adults were provided with minimal supports from schools, organisations, and agencies as they strove to provide the best opportunities for their young adults. All parents in this research emphasised that they saw this support provision as their role, that they were happy to provide the supports, and that they would continue to do so for as long as necessary. However, all felt that they were hindered in providing these supports for their autistic adolescent/adult through schools, medical professionals, and organisations failing to work collaboratively; failing to provide information to the families about adult services; and failing to include the families in decision making and planning. Research about specific practices that schools, organisations, and agencies can use to implement effective family involvement and support is critical.

Findings from this research supported the use of the TTP framework as best practice in transition-focused education (Cumming et al., 2020; O’Neill et al., 2016). Research to substantiate the use of identified evidence-based practices within the Australian education system is required and will increase the use of transition-focused education to support post-school outcomes for students with disability, including students on the autism spectrum. Importantly, research is needed within the Australian context across all five TTP domains: student-focused planning, student development, family involvement, program structures, and interagency collaboration. Based on the findings of this research, to support students on the autism spectrum, autism specific research about increasing student-focused planning to support individual students’ strengths and interests; increasing their life, social, and emotional skill development, and support within student development; and increasing family involvement, empowerment, and preparation are crucial.

Finally, similar studies that share the voices of young autistic adults need to be conducted. These studies could take a longitudinal focus on the transition-focused processes used in Australian secondary schools and how these processes support post-school QoL. Additionally, research that introduces the school’s, teachers’, and the post-school organisation’s perspectives on transition practices for young autistic adults in the Australian context would be beneficial. The same study could be conducted with different groups of young autistic adults to support further or adjust the current research’s findings. This research could also be conducted with homogeneous participant categories to determine if there are unique differences in

QoL and experiences of transition practices among young adults of different genders, level of autism diagnosis, type of schools attended, and level of family involvement.

10.6. My Personal Note Revisited

In Chapter 1, I outlined the personal positioning underpinning this research study. As part of this personal positioning, I spoke about my diverse roles relating to supporting young people on the autism spectrum: parent, teacher, teacher educator, and researcher. Throughout the research process, I have come to recognise not only the impact that each of these roles has had on the research that I have conducted, but also the significant learning that I have undergone in each of my roles.

Reflections as a parent. Being the parent of a young autistic adult provided a strong foundational motivation for my research. Going through the school to post-school transition with my son and recognising the skills that he had and the skills that he did not have as he moved into adulthood highlighted for me the importance of this specific area of research. Despite this significant personal experience, I was surprised by the findings of the research that highlighted the key role of family involvement and support in the young autistic adults' QoL. Although the experiences shared with me by other parents throughout the research were all too familiar, they were also something about which I had not expressly thought. It seems that, as the parent of a young autistic adult, "You just do what you do". When the young adult required support or needed to be "pushed", that was what the parents did, all the time weighing up the impacts on their adult child's overall wellbeing and future QoL. Furthermore, this was done with limited consistent or coordinated support from schools, medical professionals, organisations, and agencies. From this perspective, my respect and appreciation for the parents and families of the nine young adults who participated in this research are considerable. Each of the families provided constant, targeted, and well-considered support, with the goal of ensuring that their young autistic adult achieved the highest possible QoL across all domains. Their love for their child, their understanding of their child's individual and autistic characteristics, their limitless energy, and their willingness to go above and beyond to support their child for as long as necessary were inspirational.

Reflections as a teacher. For me as a teacher, the significant emphasis shared by the young adults and their parents highlighted the crucial role played by teachers in the lives of their students, and specifically in the lives of students on the autism spectrum. All the young adults and their parents spoke about the significant positive impact of a teacher who was understanding and accepting of the individual student and who went above and beyond to support the student and/or the parents. At the same time, all equally spoke about the negative impact of teachers who showed limited understanding and acceptance of the diversity of the students whom they taught. These findings highlighted the critical importance of teachers having an attitude of acceptance of diversity and a willingness to develop positive relationships with all students in the school environment.

Reflections as a teacher educator. For me as a teacher educator, this study has further highlighted the importance of teacher education not being solely based on developing teachers' academic skills and knowledge. The personal development of teachers is equally important and needs to play a significant role in teacher education. Specifically, developing strengths-based knowledges and attitudes regarding students on the autism spectrum, and regarding all students who experience any form of disadvantage, is crucial for teacher education programs.

Reflections as a researcher. The learning for me as a researcher has been significant throughout this research process. In particular, the influence of the personal positioning of the researcher on the findings of the research has been made apparent. The strengths-based focus taken throughout the research, I believe, has significantly impacted on the research findings. Thus, the important role of strengths-based qualitative studies in promoting the biopsychosocial model of disability has been highlighted. Moreover, the positive consequences of viewing disability as existing in the interaction between individual characteristics and the environment, rather than as existing within the person, have been emphasised. A further key learning for me throughout this research is the importance of universal design in methodologies for supporting the involvement of a diverse range of participants. The adjustments and strategies used throughout this research supported the participation of young autistic adults. Further adjustments in the recruitment of participants and encouraging the use of augmentative communication devices could support the participation of a broader range of young autistic adults, such as those who do not use verbal communication methods.

As a researcher, I have developed a new respect for the value and significance of theory in underpinning my thinking and work. The use of SDT was invaluable for providing the overarching framework for thinking about and working with young autistic adults. Considering wellbeing and QoL in terms of autonomy, competence, and relatedness provided the framework to consider not only what had worked well for the young adults, but also why it had worked, and how it could be extended upon. Interestingly, SDT also provided a valuable framework from which to consider the wellbeing and QoL of the parents and families (Hsiao, 2018), and for the wellbeing and QoL of teachers and other school staff as they work to support all students (Won & Chang, 2020). For me as a researcher, the framework of SDT and understanding the importance of autonomy, competence, and relatedness in my work helped me not only to relate to the experiences of the participants, but also to maintain my own wellbeing throughout the process.

Reflections across these diverse yet intersecting roles – parent, teacher, teacher educator, and researcher – have provided me with a renewed awareness that the various roles that I occupy are not conflicting roles and do not detract from one another. Rather, every experience builds my skills, my knowledge and understanding, and most importantly, my attitudes towards autistic people and their experiences. While I acknowledged the difficulty of being a nonautistic researcher in the autistic space, I hope that I achieved my goal of accurately representing the voices of the young autistic adults from a positive, strengths-based focus. I feel immense privilege in being able to share the stories of these nine inspirational young adults and their parents who have demonstrated a positive outlook on life, despite the many challenges that they have faced.

10.7. Chapter Summary

This final chapter has summarised the key findings from this study: ***How do young autistic adults perceive the interaction between secondary school transition practices and post-school quality of life?*** Overall, the research found that young autistic adults experience a positive post-school QoL, albeit with significant support provided by parents, family, and close friends. This support, however, does not detract from their QoL or the level of self-determination experienced. The young adults shared that the transition practices of schools impacted significantly on their post-school QoL. Transition practices that support the basic psychological needs of autonomy, competence, and relatedness support positive post-school QoL. Transition practices that fail to support these three basic psychological needs reduce the initial experience of post-school QoL. Importantly, young autistic adults showed high levels of resilience, and, with support, made autonomous decisions to improve their QoL when they were faced with challenges.

These findings supported the overarching conceptual framework used in this research. Considering autistic individuals' wellbeing under the umbrella of SDT and a biopsychosocial model of disability allowed a strengths-based approach to be taken to explore the experience of autism. Young adults on the autism spectrum can achieve a positive QoL through the provision of appropriate environments and supports, including appropriate secondary school transition practices. The insights provided by these young autistic adults have highlighted the interaction between secondary school practices and post-school QoL. From these findings it can be stated that it is possible to support and enable self-determination for the rest of their lives.

10.8. A Message from the Young Autistic Adults

Many of the young autistic adults, and some of the parents, had messages that they wanted to share with teachers and other young people on the autism spectrum. These messages were heartfelt statements that summarise the implications of this research in just a few simple words. For teachers, the following statements were shared. Helen asked teachers to "just sit and talk to their students individually and build an understanding" so that they can "educate themselves on the students in their cohort". She also commented that "life skills is not a study lesson", and that, while these life skills may not seem important to others, they are vital to adolescents on the autism spectrum about to transition out of school. Anne commented that teachers need "more understanding about autism" and stated emphatically, "Don't fob off a student with autism when they say they need help". For Helen and Anne's mother, she acknowledged that "teacher workload is too high", but she believed that "schools could act as an information hub for families", and that this would help to support families to support their young adult during this transition period.

Eric felt that schools could do much more to support students in "just doing life", and Piper's mother supported this with her advice to schools, "They need support strategies that help them [to] learn how to tackle and problem-solve across the functional domains, not just academia. It's those functional domains, the emotional coping mechanisms, the problem-solving, the decision making, the time management." Tamara focused very much on the teachers, stating that "I think what makes a good school is supportive teachers and teachers who are willing to understand." Tamara finished her interview with the following thought-provoking comment for teachers: "Words are so powerful; words leave scars too."

Some of the young adults wanted to share words of encouragement for other young people on the autism spectrum going through the transition to post-school and adulthood. Piper stated, "That's where we need to normalise it and create the conversation so that we can normalise it." Bruce's advice to other adults on the autism spectrum was, "Never forget who you are, because the world cannot use your disability against you", while Paul's words of wisdom were, "Be patient. Take your time. As the old saying goes, 'Good things happened to those who wait'." Finally, Frank summed up his message with the statement, "Never give up, never give up, never give up. If you believe in it, you can do it". His final words of advice to all autistic individuals were "Never let the bastards get you down."

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APPENDICES

Appendix A

Ethics Approval

[RIMS] USQ HRE - H19REA013 - Ethics Application Approval Notice (Expedited Review)

Inbox

human.ethics@usq.edu.au Fri, May 10, 2019, 8:39 AM

to Q8744530

Dear Karen

I am pleased to confirm your Human Research Ethics (HRE) application has now been reviewed by the University's Expedited Review process. As your research proposal has been deemed to meet the requirements of the National Statement on Ethical Conduct in Human Research (2007), ethical approval is granted as follows.

Project Title: H19REA013 - Self-determination for the rest of my life: Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life
Approval date: 10/05/2019
Expiry date: 10/05/2022
USQ HREC status: Approved with conditions

(a) responsibly conduct the project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments made to the proposal;
(b) advise the University (email: ResearchIntegrity@usq.edu.au) immediately of any complaint pertaining to the conduct of the research or any other issues in relation to this project which may warrant review of the ethical approval of this project;
(c) promptly report any adverse events or unexpected outcomes to the University

(email: ResearchIntegrity@usq.edu.au) and take prompt action to deal with any unexpected risks;

(d) make submission for any amendments to the project and obtain approval prior to implementing such changes;

(e) provide a progress 'milestone report' when requested and at least for every year of approval;

(f) provide a final 'milestone report' when the project is complete.

(g) promptly advise the University if the project has been discontinued, using a final 'milestone report'.

Additional conditionals of approval for this project are:

(a) Nil.

Please note that failure to comply with the conditions of this approval or requirements of the Australian Code for the Responsible Conduct of Research, 2018, and the National Statement on Ethical Conduct in Human Research, 2007 may result in withdrawal of approval for the project.

If you have any questions or concerns, please don't hesitate to make contact with an Ethics Officer.
Congratulations on your ethical approval! Wishing you all the best for success!

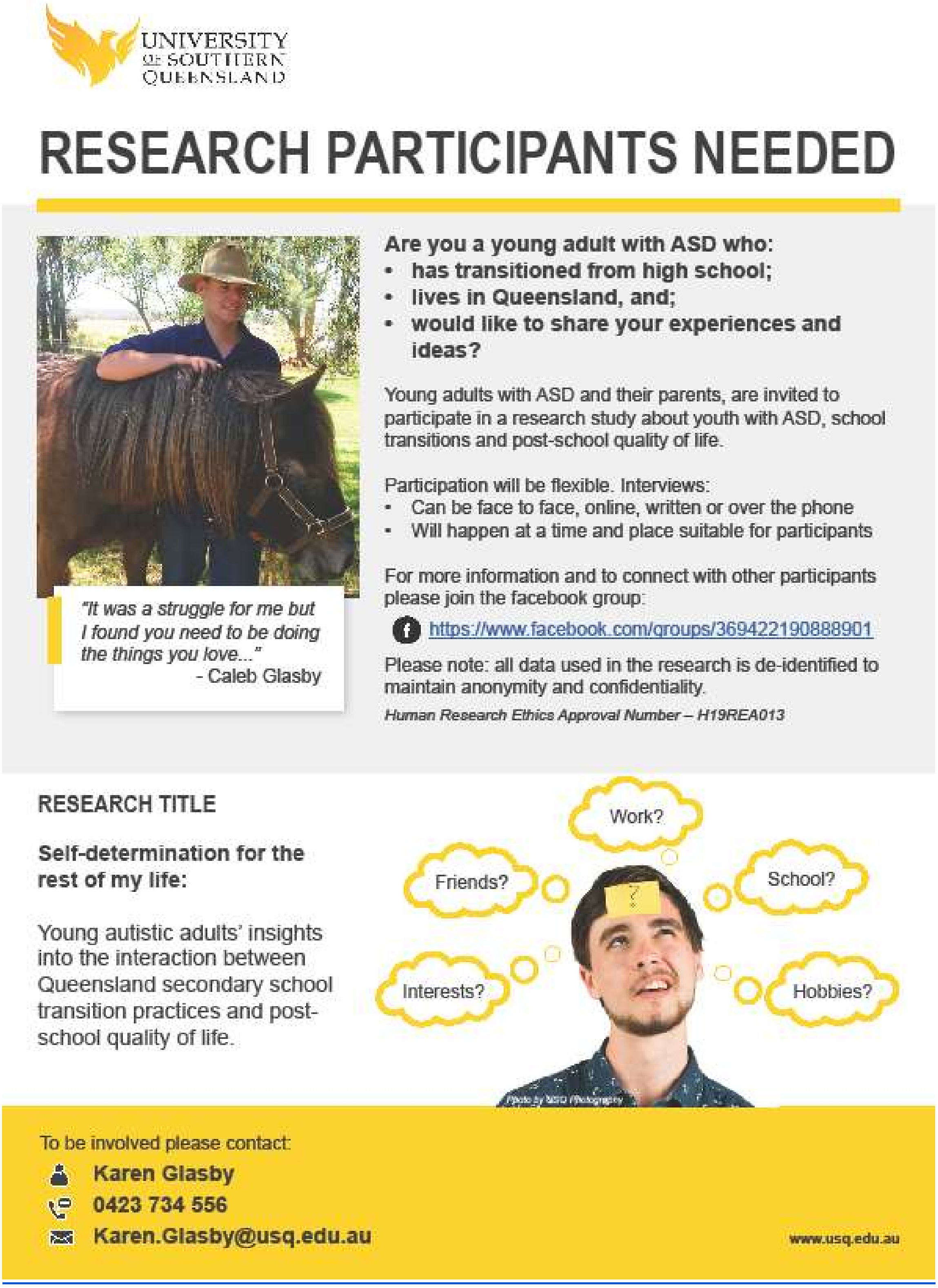
Kind regards,

Human Research Ethics

University of Southern Queensland
Toowoomba – Queensland – 4350 – Australia
Ph: 07 4687 5703 – Ph: 07 4631 2690 – Email: human.ethics@usq.edu.au

Appendix B

Participant Recruitment Flyer



UNIVERSITY OF SOUTHERN QUEENSLAND

RESEARCH PARTICIPANTS NEEDED

Are you a young adult with ASD who:

- **has transitioned from high school;**
- **lives in Queensland, and;**
- **would like to share your experiences and ideas?**

Young adults with ASD and their parents, are invited to participate in a research study about youth with ASD, school transitions and post-school quality of life.

Participation will be flexible. Interviews:

- Can be face to face, online, written or over the phone
- Will happen at a time and place suitable for participants

For more information and to connect with other participants please join the facebook group:

https://www.facebook.com/groups/369422190888901

Please note: all data used in the research is de-identified to maintain anonymity and confidentiality.

Human Research Ethics Approval Number – H19REA013

> *"It was a struggle for me but I found you need to be doing the things you love..."*
> - Caleb Glasby

RESEARCH TITLE

Self-determination for the rest of my life:

Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life.

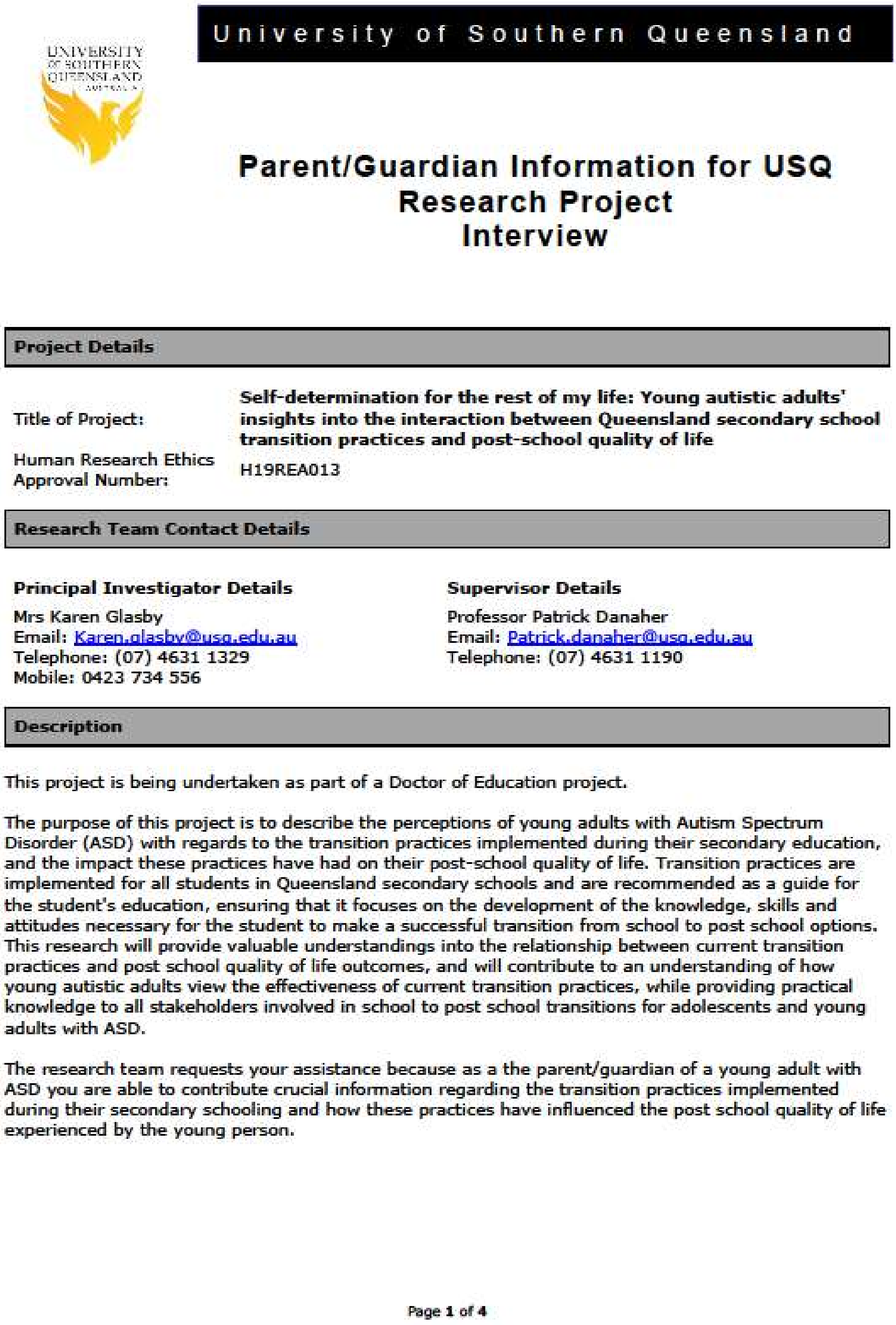
To be involved please contact:

Karen Glasby
0423 734 556
Karen.Glasby@usq.edu.au

www.usq.edu.au

Appendix C

Parent/carer Information Sheet



University of Southern Queensland

Parent/Guardian Information for USQ Research Project Interview

Project Details

Title of Project:	**Self-determination for the rest of my life: Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life**
Human Research Ethics Approval Number:	H19REA013

Research Team Contact Details

Principal Investigator Details	**Supervisor Details**
Mrs Karen Glasby	Professor Patrick Danaher
Email: Karen.glasby@usq.edu.au	Email: Patrick.danaher@usq.edu.au
Telephone: (07) 4631 1329	Telephone: (07) 4631 1190
Mobile: 0423 734 556	

Description

This project is being undertaken as part of a Doctor of Education project.

The purpose of this project is to describe the perceptions of young adults with Autism Spectrum Disorder (ASD) with regards to the transition practices implemented during their secondary education, and the impact these practices have had on their post-school quality of life. Transition practices are implemented for all students in Queensland secondary schools and are recommended as a guide for the student's education, ensuring that it focuses on the development of the knowledge, skills and attitudes necessary for the student to make a successful transition from school to post school options. This research will provide valuable understandings into the relationship between current transition practices and post school quality of life outcomes, and will contribute to an understanding of how young autistic adults view the effectiveness of current transition practices, while providing practical knowledge to all stakeholders involved in school to post school transitions for adolescents and young adults with ASD.

The research team requests your assistance because as a the parent/guardian of a young adult with ASD you are able to contribute crucial information regarding the transition practices implemented during their secondary schooling and how these practices have influenced the post school quality of life experienced by the young person.

Participation

Your participation will involve up to 2 interviews that will take no more than 1 hour of your time each.

The time and venue for the interview will be agreed upon by you and the principal investigator. If preferred, the interview can be undertaken online or by phone at a date and time that is agreed upon by you and the principal investigator.

Interview questions will be provided to you prior to undertaking the interview.

Your responses in the interview will be audio recorded and transcribed for later analysis. The transcription process will involve either the researcher, or a USQ endorsed transcription company which adheres to the Australian Privacy Principles and international equivalents, transcribing the full interview. You will be provided with a written copy of the transcribed interview and will be given the opportunity to approve the final interview before the interview data is analysed and used in the research project.

Your participation in this project is entirely voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. You may also request that any data collected about you be withdrawn and confidentially destroyed. If you do wish to withdraw from this project or withdraw data collected about you, please contact the Research Team (contact details at the top of this form).

Your decision whether you take part, do not take part, or to take part and then withdraw, will in no way impact your current or future relationship with the University of Southern Queensland.

Expected Benefits

It is expected that this project will directly benefit you, the participant, through encouraging and supporting you to engage in a critical self-reflection regarding the young person with ASD and their transition to post-school options and how they may use the knowledge, skills, attitudes and preferences that they developed throughout their secondary education to enhance these options.

It may also benefit the educational communities understanding of the nature and benefits of transition programs and how they can support young people with ASD in preparation for post-school life. Through this greater understanding and knowledge, schools and staff will be given the opportunity to develop and effectively implement effective transition plans. This may contribute to an overall improvement in post-school outcomes for young people with ASD.

Risks

There are minimal risks associated with your participation in this project. These include:

- The risk of experiencing anxiety or stress due to the nature of participating in the interview process
- The time commitment needed to participate in the interview process
- The risk of experiencing anxiety or stress as a result of talking about your child/ward's experiences at school and/or life after school

All participants within the research study will be voluntary participants who have given informed consent to participate. All participants will be reminded at the beginning of the interview that their

participation is voluntary and confidential and that they may choose to end the interview at any time or for any reason.
The intent of the research is not to focus on the negative aspects of schooling or post-school life, but to focus on the strengths, skills, knowledge and interests that the young person and their family have developed throughout the young person's secondary schooling and transition to life post-school.

Sometimes thinking about the sorts of issues raised in the interview can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately please contact:

- beyondblue – 1300 22 4636
- Lifeline – 13 11 14
- Darling Downs ASD Carer Support Group – 4646 2899
- Autism Queensland Dalby and Western Downs Autism Spectrum Disorder Support Group – 0466 720 018
- USQ Toowoomba Psychology and Counselling Clinic 07 4632 1763
- USQ Ipswich Psychology and Counselling Clinic 07 3812 6163

You may also wish to consider consulting your General Practitioner (GP) for additional support.

Privacy and Confidentiality

All comments and responses will be treated confidentially unless required by law.

A pseudonym (a name that can be used instead of your real name) will be used throughout the research project to provide confidentiality and anonymity. You, the participant, may chose this pseudonym or one will be provided for you.

Any data collected as a part of this project will be stored securely as per University of Southern Queensland's Research Data Management policy. All data will be stored for the requisite 15 year period before being destroyed. The data collected in this research project may be made available for future research purposes within this field. Only non-identifiable data will be shared (i.e. data available under the chosen pseudonym).

During this period the data will be stored in a locked filing cabinet in the researcher's office at USQ Toowoomba. All electronic files will be stored on the researcher's password-protected laptop at USQ Toowoomba. The data will also be stored in a secure, password-protected database on the recommended USQ server and cloud storage - ReDBank Cloud. If, at any time, it is necessary for data to be accessed by the researcher at home, the data will be kept in a locked filing cabinet and on the password-protected USQ work laptop.

Audio recordings of the semi-structured interviews will be made for transcription as part of the original data collection. Audio recordings may also be made of informed participant consent if participants choose to use this method in place of written consent. The transcription of all audio recordings will be carried out by the principal investigator. You will be provided with a copy of the interview transcript for review and endorsement prior to inclusion in the project data. The transcribed data will be provided to you within a 4 week timeframe and you will be given a further 2 weeks to request any changes to the transcript before the data is included in the project for analysis.

The data collected throughout the research project will be used for academic publishing purposes. If you choose, any written articles can be provided to you, the participant, your parent/guardian and advocate, for you to read and consent to them being submitted for publishing.

Once the project interviews, transcription and analysis has been conducted the researcher will contact you to set up a time for a final meeting. During this meeting the researcher will provide you with both a written copy and verbal summary of the information that will be included in the final thesis.

Any data collected as a part of this project will be stored securely as per University of Southern Queensland's Research Data Management policy.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate in this project. Please return your signed consent form to a member of the Research Team prior to participating in your interview.

Alternatively, you may provide informed consent verbally at the beginning of the first observation or interview. Audio recordings will be made of informed participant consent if participants choose to use this method in place of written consent.

Questions or Further Information about the Project

Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

Concerns or Complaints Regarding the Conduct of the Project

If you have any concerns or complaints about the ethical conduct of the project you may contact the University of Southern Queensland Manager of Research Integrity and Ethics on +61 7 4631 2214 or email researchintegrity@usq.edu.au. The Manager of Research Integrity and Ethics is not connected with the research project and can facilitate a resolution to your concern in an unbiased manner.

Thank you for taking the time to help with this research project. Please keep this sheet for your information.

Appendix D

Information sheet advocate

University of Southern Queensland

Advocate Information for USQ Research Project Interview

Project Details

Title of Project: **Self-determination for the rest of my life: Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life**

Human Research Ethics Approval Number: H19REA013

Research Team Contact Details

Principal Investigator Details

Mrs Karen Glasby
Email: Karen.glasby@usq.edu.au
Telephone: (07) 4631 1329
Mobile: 0423 734 556

Supervisor Details

Professor Patrick Danaher
Email: Patrick.danaher@usq.edu.au
Telephone: (07) 4631 1190

Description

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The research team requests your assistance to act as an advocate for the young adult with ASD as they participate in the research process.

Participation

Your participation will involve no more than 5 interviews that will take no more than 45 mins of your time for each interview. (The final decision on number and length of interviews will be an agreed decision between yourself, the participant and the principal researcher).

The time and venue for the interviews will be agreed upon by you, the participant and the principal investigator. If the participant prefers, the interview can be undertaken online or by phone at a date and time that is agreed upon by you, the participant and the principal investigator. For a phone interview you will be present with the participant throughout the phone interview.

Your role during the interview process will include:
- Monitoring the level of stress and anxiety being experienced by the young person as they participate in the interview process, and immediately reporting an increasing levels of stress and/or anxiety to the researcher
- Continuing to monitor the young person's willingness to participate in the interview process and immediately reporting any concerns to the researcher
- Discuss with the researcher more suitable methods of engaging with the young person during the interview process
- Supporting the young person to determine appropriate days, times and venues for the interviews to occur and assisting the young person (if necessary) to attend these interviews.

Please note: It is a requirement of this research that, as the advocate, you will NOT directly or indirectly answer questions during the interview process. The interview questions will be answered by the young adult with ASD.

Your participation in this project is entirely voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. You may also request that any data collected about you be withdrawn and confidentially destroyed. If you do wish to withdraw from this project or withdraw data collected about you, please contact the Research Team (contact details at the top of this form).

Your decision whether you take part, do not take part, or to take part and then withdraw, will in no way impact your current or future relationship with the University of Southern Queensland.

Expected Benefits

It is expected that this project will directly benefit the participant through encouraging and supporting them to engage in a critical self-reflection regarding their transition to post-school options and how they may use the knowledge, skills, attitudes and preferences that they developed throughout their secondary education to enhance these options.
It may also benefit the educational communities understanding of the nature and benefits of transition programs and how they can support young people with ASD in preparation for post-school life.
Through this greater understanding and knowledge, schools and staff will be given the opportunity to develop and effectively implement effective transition plans. This may contribute to an overall improvement in post-school outcomes for young people with ASD.
Participation in the project will allow you, the advocate, to support the young adult with ASD to use their voice to provide crucial information regarding transition practices implemented during secondary schooling and how these practices have influenced their post school quality of life.

Risks

There are minimal risks associated with your participation in this project. These include:
- The risk of experiencing anxiety or stress due to the nature of supporting the young person during the interview process
- The time commitment needed to support the participate during the interview process
- The risk of experiencing anxiety or stress as a result of hearing the young person talk about their experiences at school and/or life after school

If your parents choose not to participate in the research, you are still welcome to participate if you are over 18 and legally able to give consent.

The interview will take place at a time and venue that is suitable for you. The time and venue will be agreed on by you, the participant, your nominated advocate, and the principal investigator. If preferred, the interview can be undertaken online or by phone at a date and time that is agreed upon by you, your advocate and the principal investigator.

Interview questions will be provided to you prior to the interview.

Your responses in the interview will be audio recorded and transcribed for later analysis. The transcription process will involve either the researcher, or a USQ endorsed transcription company which adheres to the Australian Privacy Principles and international equivalents, taking the full interview recording and writing it down in words. You will be provided with a copy of the written interview, or the researcher will read through the interview with you. You will then be asked to say if you are happy for the final interview to be used in the research project.

Your participation in this project is entirely voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. If you do wish to withdraw from this project or withdraw data collected about you, please contact the Research Team (contact details at the top of this form).

Your decision whether you take part, do not take part, or to take part and then withdraw, will in no way impact your current or future relationship with the University of Southern Queensland.

Expected Benefits

It is expected that this project will directly benefit you through encouraging and supporting you, the participant, to engage in a critical self-reflection regarding to your post-school options and how you can use the knowledge, skills, attitudes and preferences that you have developed throughout your secondary education to enhance these options.
It may also benefit the educational communities understanding of the nature and benefits of transition programs and how they can support young people with ASD in preparation for post-school life. Through this greater understanding and knowledge, schools and staff will be given the opportunity to develop and effectively implement effective transition plans. This may contribute to an overall improvement in post-school outcomes for young people with ASD.

Risks

There are some risks associated with your participation in this project. These include:

- The risk of experiencing anxiety or stress due to the nature of participating in interviews
- The risk of experiencing anxiety or stress as a result of talking about school and/or life after school
- The risk of experiencing anxiety or stress due to the presence of the researcher
- The time commitment needed to participate in the interviews

All participants within the research study will be voluntary participants who have given informed consent to participate. All participants will be reminded at the beginning of the interview/s that their participation is voluntary and confidential and that they may choose to end the interview at any time or for any reason.

The intent of the research is not to focus on the negative aspects of schooling or post-school life, but to focus on the strengths, skills, knowledge and interests that you, the participant, have developed throughout your secondary schooling and can take into life post-school.

Both your parents and/or your nominated advocate will also be aware of these possible risks for you, as the participant and will be encouraged to speak to the researcher on your behalf if they believe your stress or anxiety levels are increasing. The researcher will work very closely with yourself, as well as your parent/guardian and/or advocates, to develop the most effective strategies to support you, the participant. If you are not comfortable speaking with the researcher, your parent/guardian and/or advocate will be able to talk to the researcher on your behalf.

If you feel anxious or stressed either before, during or after the interview/s please contact the following support services. Your parent/guardian and advocate will also be provided with these details and will be able to help you access these services if necessary:

- beyondblue – 1300 22 4636
- Lifeline – 13 11 14
- Headspace (Toowoomba) – 4639 9000
- Toowoomba support group for Autism Spectrum Disorder – 4632 8922
- Autism Queensland Dalby and Western Downs Autism Spectrum Disorder Support Group – 0466 720 018
- USQ Toowoomba Psychology and Counselling Clinic 07 4632 1763
- USQ Ipswich Psychology and Counselling Clinic 07 3812 6163

Please add any support people that you would typically talk to during times of stress or anxiety (e.g. your general practitioner, private counsellor or psychologist or family and friends):

- ____
- ____
- ____

You, the participant, will work closely with the researcher to determine the best times and locations for any interviews conducted during the research. You will be given the opportunity to:

- Spend time getting to know the researcher prior to any interviews
- Choose the time, location, scheduling and details of how the interviews will be conducted (e.g. face to face, through a computer, written or verbal questions).
- Choose the length and number of interviews.
- Take part in a 'trial run' interview, so that you know what to expect during the interview process and are able to request any changes that you feel may be needed.
- Bring an advocate or support person to the interview (e.g. Parents, support worker or friend).
- Access a 'safe place' to go to either during or after the interview to ensure you are provided with the time to process the interview questions and any emotions this may have caused.
- You will be provided with multiple methods for requesting an end to an interview (e.g. verbally, the use of visuals, a physical sign or gesture).

Privacy and Confidentiality

All comments and responses will be treated confidentially unless required by law.

A pseudonym (a name that can be used instead of your real name) will be used throughout the research project to provide confidentiality and anonymity. You, the participant, may chose this pseudonym or one will be provided for you.

Any data collected as a part of this project will be stored securely as per University of Southern Queensland's Research Data Management policy. All data will be stored for the requisite 15 year period before being destroyed. The data collected in this research project may be made available for future research purposes within this field. Only non-identifiable data will be shared (i.e. data available under the chosen pseudonym).

During this period the data will be stored in a locked filing cabinet in the researcher's office at USQ Toowoomba. All electronic files will be stored on the researcher's password-protected laptop at USQ Toowoomba. The data will also be stored in a secure, password-protected database on the recommended USQ server and cloud storage - ReDBank Cloud. If, at any time, it is necessary for data to be accessed by the researcher at home, the data will be kept in a locked filing cabinet and on the password-protected USQ work laptop.

Audio recordings of the semi-structured interviews will be made for transcription as part of the original data collection. Audio recordings may also be made of informed participant consent if participants choose to use this method in place of written consent. The transcription of all audio recordings will be carried out by the principal investigator. You will be provided with a copy of the interview transcript for review and endorsement prior to inclusion in the project data. The transcribed data will be provided to you within a 4 week timeframe and you will be given a further 2 weeks to request any changes to the transcript before the data is included in the project for analysis.

The data collected throughout the research project will be used by the researcher to share the findings with other researchers and interested people. Any written articles will be provided to you, the participant, your parent/guardian and advocate, for you to read prior to publishing.

Once the project interviews, transcription and analysis has been conducted the researcher will contact you to set up a time for a final meeting. During this meeting the researcher will provide you with both a written copy and verbal summary of the information that will be included in the final thesis.

Any data collected as a part of this project will be stored securely as per University of Southern Queensland's Research Data Management policy.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate in this project. Please return your signed consent form to a member of the Research Team prior to participating in your interview.

Alternatively, you may provide informed consent verbally at the beginning of the first observation or interview. Audio recordings will be made of informed participant consent if participants choose to use this method in place of written consent.

Questions or Further Information about the Project

Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

Concerns or Complaints Regarding the Conduct of the Project

If you have any concerns or complaints about the ethical conduct of the project you may contact the University of Southern Queensland Manager of Research Integrity and Ethics on +61 7 4631 2214 or email researchintegrity@usq.edu.au. The Manager of Research Integrity and Ethics is not connected with the research project and can facilitate a resolution to your concern in an unbiased manner.

Thank you for taking the time to help with this research project. Please fill in the additional support services you wish to include and return a copy of this completed sheet with the consent form. You will be provided with a copy of this completed participant information sheet for your information.

Appendix E

Participant Information Sheet

University of Southern Queensland

Participant Information for USQ Research Project Interview

Project Details

Title of Project:	**Self-determination for the rest of my life: Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life**
Human Research Ethics Approval Number:	H19REA013

Research Team Contact Details

Principal Investigator Details
Mrs Karen Glasby
Email: Karen.glasby@usq.edu.au
Telephone: (07) 4631 1329
Mobile: 0423 734 556

Supervisor Details
Professor Patrick Danaher
Email: Patrick.danaher@usq.edu.au
Telephone: (07) 4631 1190

Description

This project is being undertaken as part of a Doctor of Education project.

The purpose of this project is to describe how you, a young adult with Autism Spectrum Disorder (ASD), feels about the transition practices used during your time in secondary school, and the way these practices may have influenced your post-school quality of life. This research will provide valuable understanding about the relationship between transition practices and post school quality of life outcomes. It will contribute to an understanding of whether young autistic adults see the transition practices used as being helpful in their move to post school options such as getting a job, living independently, having friends and being a part of their community. It is hoped that this will provide practical knowledge to all stakeholders – schools, parents and support services, involved in school to post school transitions for adolescents and young adults with ASD.

The research team requests your assistance because as a young adult with ASD you are able to contribute crucial information regarding the transition practices implemented during your secondary schooling and how these practices have influenced your post school quality of life.

Participation

Your participation will involve no more than 5 interviews that will take no more than 45 mins of your time for each interview. (The final decision on number and length of interviews will be your decision). You are encouraged to nominate an advocate to attend these interviews with you. The advocate can be a family member, support person or friend who knows you well and can consent to participating in the research project. The advocate will provide support for you throughout the interview process but will not answer the interview questions for you.

Appendix F

Participant Information Sheet: Easy read

University of Southern Queensland

Easy Read Participant Information sheet for USQ Research Project Interview

Project Details

Title of Project:	**Self-determination for the rest of my life: Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life**
Human Research Ethics Approval Number:	H19REA013

Research Team Contact Details

Karen is the main researcher
To talk to Karen
Ring 0423 734 556
Email Karen.glasby@usq.edu.au

You can also ring Karen's teacher
His name is Professor Patrick Danaher
To contact Patrick
Ring 4331 1190
Email Patrick.danaher@usq.edu.au

Description

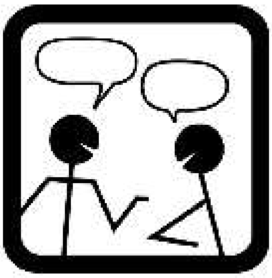
This project is so that you can tell everyone how you feel about your life as an adult

It will help Karen and other people understand how you feel about leaving school and starting your life as an adult

And about how school helped you, or didn't help you, to do the things you want

If you are a young adult with autism, you have a lot of important information to tell us about life after school

Participation



You will talk to Karen in an **interview**

An interview is where Karen will ask you questions and you will tell her your answers

The questions will be about your life after school, and what you learned in school to help you do the things you want

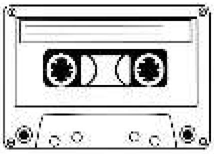
You can choose how long the interviews are, and how many you have

You can nominate an **advocate**

An advocate is someone can help you feel comfortable in the interviews

The advocate is someone who can help you if you are feeling anxious or stressed

The advocate will not answer the questions for you



The interview will be recorded so Karen can listen to it later

She will write down what you say from the recording.
This is called a **transcript**

You doing the interviews is **voluntary**

Voluntary means that it is your choice - you can do it if you want, but you do not have to do it

If you want, Karen will give you a copy of the questions before the interview

If you start an interview and decide you don't want to do it, you can choose to stop

You choose to stop the interview by telling Karen or your advocate

No-one will be upset if you decide to stop the interview

Expected Benefits

You might find talking in the interviews makes you feel good

It might help you:

- Think about the good things you are doing in your life
- Think about the things you like to do
- Help you remember the things you learned at school
- Help everyone to know how to help you achieve the things you want in life

Your ideas will help:

- Schools to know how to help other people with autism
- Parents of people with autism to know how to help their child when they finish school

Risks

Sometimes you might find the interviews make you anxious or stressed

You might feel anxious or stressed when talking about:

- School
- Life after school

You might feel anxious or stressed because you don't know Karen

You might feel anxious or stressed about how long the interview is

If you feel anxious or stressed you can tell Karen

You can tell your parents or your advocate, and they will tell Karen

You can also talk to these groups or people if you feel anxious or stressed

- Beyondblue 1300 22 4636
- Lifeline 13 11 14
- Headspace 4639 9000
- Toowoomba support group for ASD 4632 8922
- Autism Queensland Dalby and Western Downs ASD Support Group 0466 720 018
- USQ Toowoomba Psychology and Counselling Clinic 4632 1763

- USQ Ipswich Psychology and Counselling Clinic 3812 6163

Add support people that you talk to when stressed or anxious

- ____
- ____
- ____

You can:

Spend time getting to know Karen before the interview

Choose the time and place for the interview

Choose how long the interview goes for

Choose how to do the interview – talk to Karen online, by phone or by writing your answers

Choose to use visuals in the interview or

Bring photos to the interview to talk about

Bring an advocate or support person to the interview e.g. Parents, support worker or friend

Choose a 'safe place' to go to during the interview if you are feeling anxious or stressed

Have a practice interview, so that you know what to expect when doing an interview

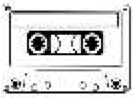
Privacy and Confidentiality

Everything you say will be **confidential,** unless it means you are in danger

Confidential means Karen will not tell anyone else what you say

A made up name can be used instead of your real name

You can choose the name you want Karen to use



The interview will be recorded so Karen can listen to it later

She will write down what you say from the recording. This is called a **transcript**

You can ask to read the transcript

The recording and transcript will be kept safely so no one else can hear or see them

Karen may share what you say with other researchers without using your real name.

You can tell Karen if you don't want her to do this

Consent to Participate

You can say you want to be a part of the research by:

Signing the consent form

Or

Telling Karen

Concerns or complaints about the project

If you have any concerns or complaints about the project

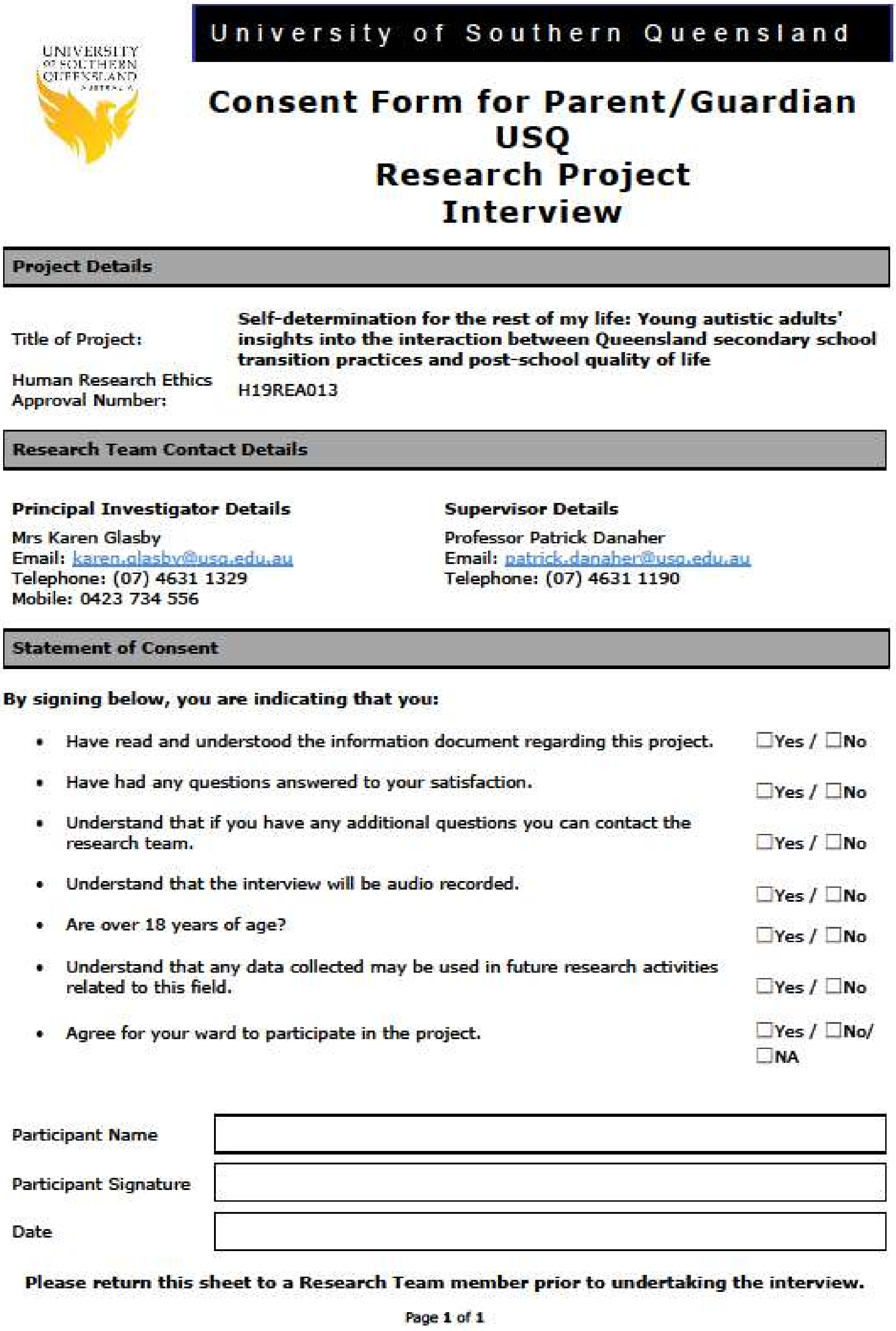
Contact the University of Southern Queensland

(07) 4631 2214

Email researchintegrity@usq.edu.au.

Appendix G

Parent/carer Consent Form



University of Southern Queensland

Consent Form for Parent/Guardian USQ Research Project Interview

Project Details

Title of Project:	**Self-determination for the rest of my life: Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life**
Human Research Ethics Approval Number:	H19REA013

Research Team Contact Details

Principal Investigator Details	**Supervisor Details**
Mrs Karen Glasby	Professor Patrick Danaher
Email: karen.glasby@usq.edu.au	Email: patrick.danaher@usq.edu.au
Telephone: (07) 4631 1329	Telephone: (07) 4631 1190
Mobile: 0423 734 556	

Statement of Consent

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.	☐Yes / ☐No
- Have had any questions answered to your satisfaction.	☐Yes / ☐No
- Understand that if you have any additional questions you can contact the research team.	☐Yes / ☐No
- Understand that the interview will be audio recorded.	☐Yes / ☐No
- Are over 18 years of age?	☐Yes / ☐No
- Understand that any data collected may be used in future research activities related to this field.	☐Yes / ☐No
- Agree for your ward to participate in the project.	☐Yes / ☐No/ ☐NA

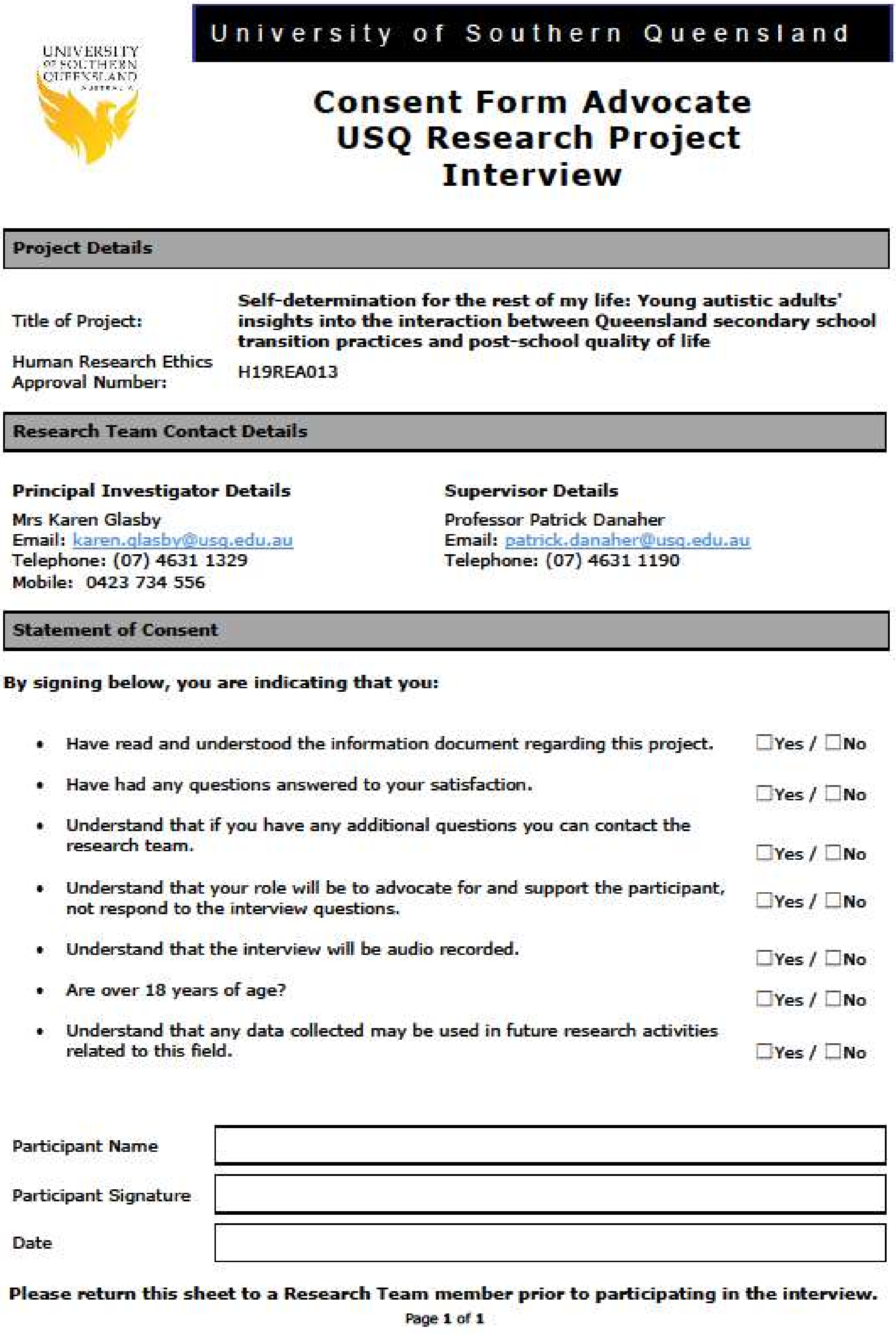
Participant Name	
Participant Signature	
Date	

Please return this sheet to a Research Team member prior to undertaking the interview.

Page **1** of **1**

Appendix H

Advocate Consent Form



University of Southern Queensland

Consent Form Advocate USQ Research Project Interview

Project Details

Title of Project: **Self-determination for the rest of my life: Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life**

Human Research Ethics Approval Number: H19REA013

Research Team Contact Details

Principal Investigator Details
Mrs Karen Glasby
Email: karen.glasby@usq.edu.au
Telephone: (07) 4631 1329
Mobile: 0423 734 556

Supervisor Details
Professor Patrick Danaher
Email: patrick.danaher@usq.edu.au
Telephone: (07) 4631 1190

Statement of Consent

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project. ☐Yes / ☐No
- Have had any questions answered to your satisfaction. ☐Yes / ☐No
- Understand that if you have any additional questions you can contact the research team. ☐Yes / ☐No
- Understand that your role will be to advocate for and support the participant, not respond to the interview questions. ☐Yes / ☐No
- Understand that the interview will be audio recorded. ☐Yes / ☐No
- Are over 18 years of age? ☐Yes / ☐No
- Understand that any data collected may be used in future research activities related to this field. ☐Yes / ☐No

Participant Name

Participant Signature

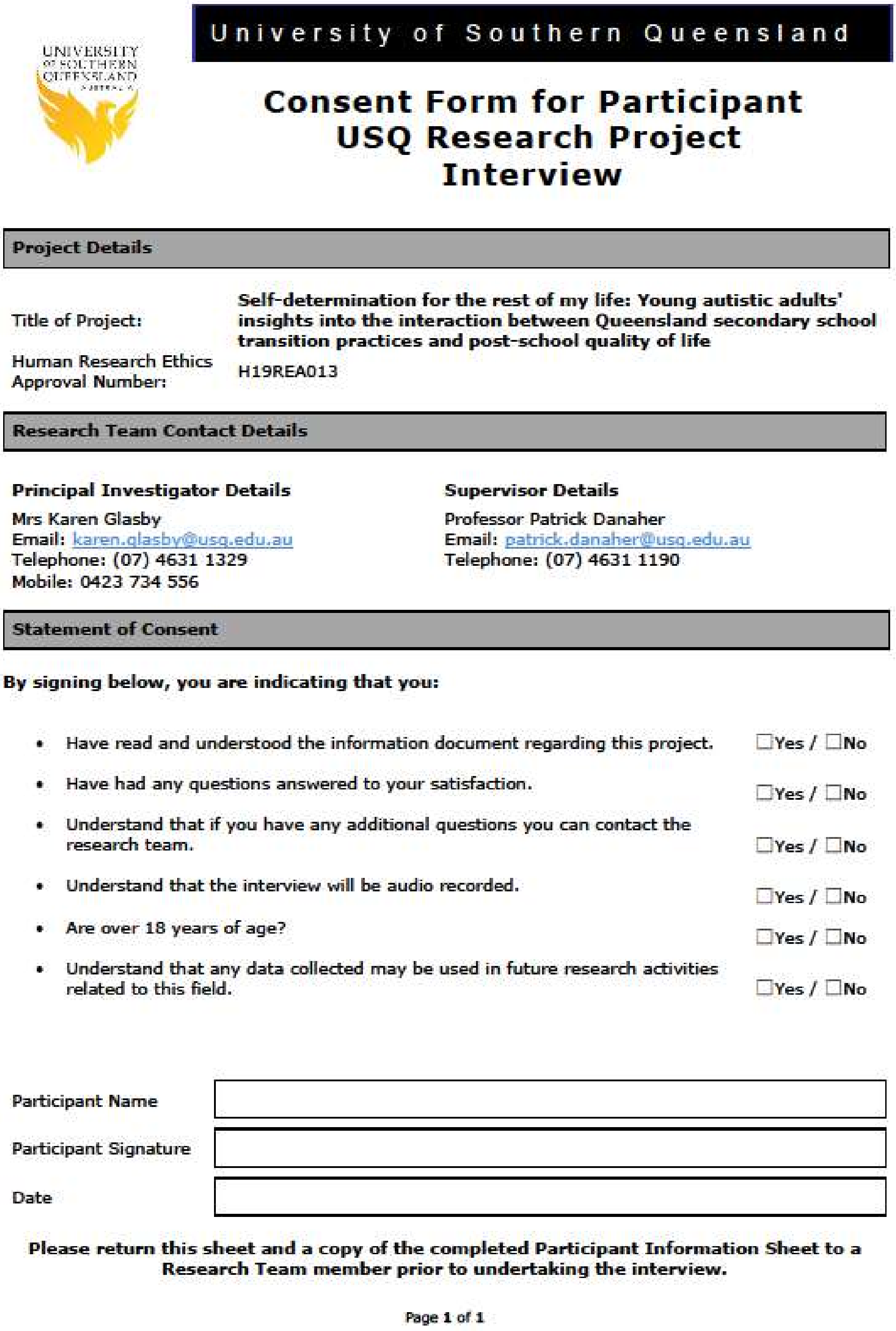
Date

Please return this sheet to a Research Team member prior to participating in the interview.

Page **1** of **1**

Appendix I

Participant Consent Form



University of Southern Queensland

UNIVERSITY OF SOUTHERN QUEENSLAND AUSTRALIA

Consent Form for Participant USQ Research Project Interview

Project Details

Title of Project: **Self-determination for the rest of my life: Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life**

Human Research Ethics Approval Number: H19REA013

Research Team Contact Details

Principal Investigator Details	**Supervisor Details**
Mrs Karen Glasby	Professor Patrick Danaher
Email: karen.glasby@usq.edu.au	Email: patrick.danaher@usq.edu.au
Telephone: (07) 4631 1329	Telephone: (07) 4631 1190
Mobile: 0423 734 556	

Statement of Consent

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project. ☐Yes / ☐No
- Have had any questions answered to your satisfaction. ☐Yes / ☐No
- Understand that if you have any additional questions you can contact the research team. ☐Yes / ☐No
- Understand that the interview will be audio recorded. ☐Yes / ☐No
- Are over 18 years of age? ☐Yes / ☐No
- Understand that any data collected may be used in future research activities related to this field. ☐Yes / ☐No

Participant Name

Participant Signature

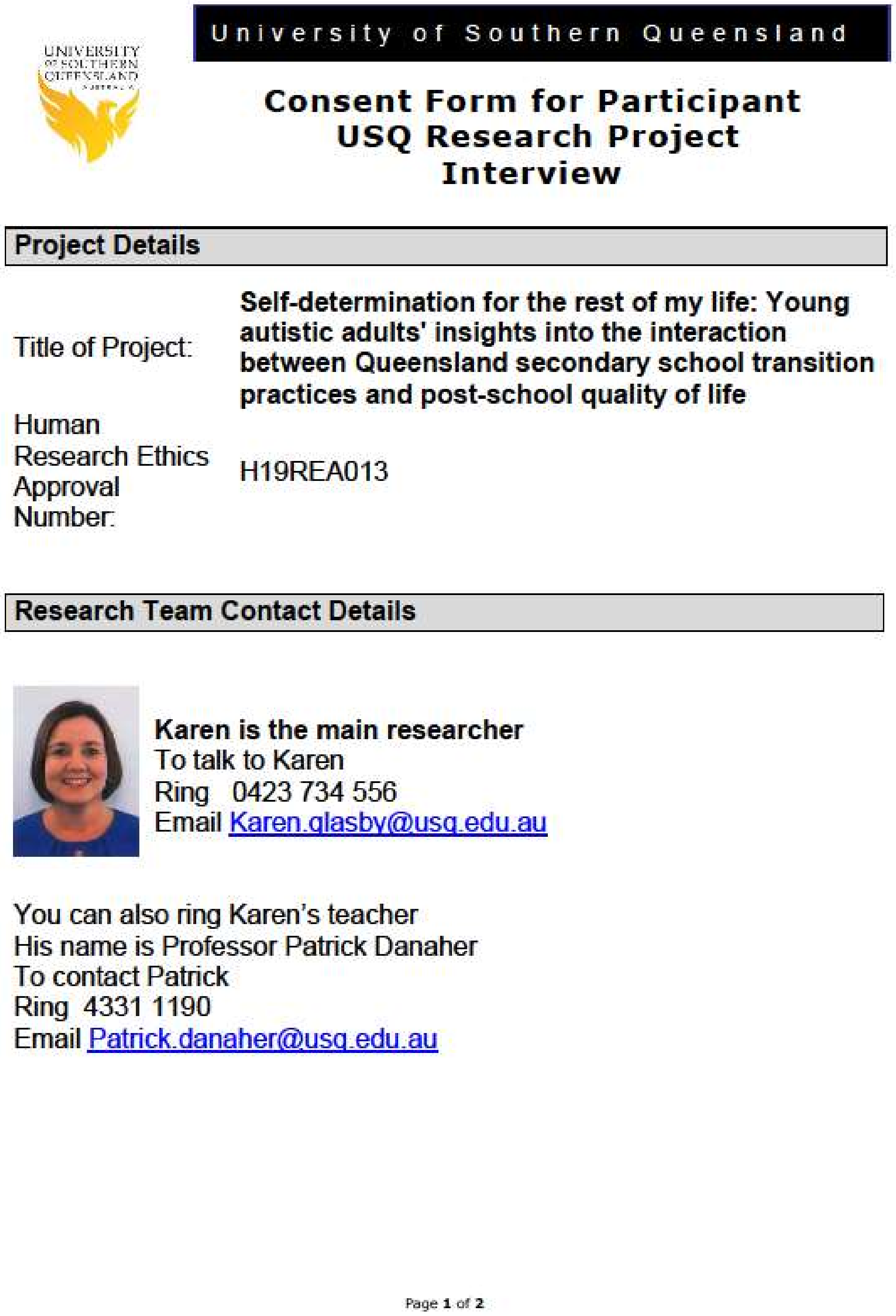
Date

Please return this sheet and a copy of the completed Participant Information Sheet to a Research Team member prior to undertaking the interview.

Page **1** of **1**

Appendix J

Participant Consent Form: Easy read



University of Southern Queensland

Consent Form for Participant
USQ Research Project
Interview

Project Details

Title of Project:	**Self-determination for the rest of my life: Young autistic adults' insights into the interaction between Queensland secondary school transition practices and post-school quality of life**
Human Research Ethics Approval Number:	H19REA013

Research Team Contact Details

Karen is the main researcher
To talk to Karen
Ring 0423 734 556
Email Karen.glasby@usq.edu.au

You can also ring Karen's teacher
His name is Professor Patrick Danaher
To contact Patrick
Ring 4331 1190
Email Patrick.danaher@usq.edu.au

Statement of Consent

By signing below, you are saying that you:

- Have read and understood the information about this project. ☐Yes ☐No
- Have had asked any questions that you have and have had them answered ☐Yes ☐No
- Understand that if you have any other questions you can contact the researcher Karen. ☐Yes ☐No
- Understand that the interview will be recorded. ☐Yes ☐No
- Are over 18 years of age? ☐Yes ☐No
- Understand that what you say may be used to help other researchers in the future ☐Yes ☐No

Participant Name

Participant Signature

Date

Please give this consent form and the Information sheet to Karen before, or at the beginning of, your first interview

All participants within the research study will be voluntary participants who have given informed consent to participate. All participants will be reminded at the beginning of the interview that their participation is voluntary and confidential and that they may choose to end the interview at any time or for any reason.
The intent of the research is not to focus on the negative aspects of schooling or post-school life, but to focus on the strengths, skills, knowledge and interests that the young person and their family have developed throughout the young person's secondary schooling and transition to life post-school.

Sometimes thinking about the sorts of issues raised in the interview can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately please contact:

- beyondblue – 1300 22 4636
- Lifeline – 13 11 14
- Darling Downs ASD Carer Support Group – 4646 2899
- Autism Queensland Dalby and Western Downs Autism Spectrum Disorder Support Group – 0466 720 018
- USQ Toowoomba Psychology and Counselling Clinic 07 4632 1763
- USQ Ipswich Psychology and Counselling Clinic 07 3812 6163

You may also wish to consider consulting your General Practitioner (GP) for additional support.

Privacy and Confidentiality

All comments made by you, to the researcher, will be treated confidentially unless required by law and will be used solely to support the participation and well-being of the young adult with ASD during the research process.

There will be no recorded data of your comments or discussions with the researcher for this project.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate in this project. Please return your signed consent form to a member of the Research Team prior to participating in your interview.

Alternatively, you may provide informed consent verbally at the beginning of the first observation or interview. Audio recordings will be made of informed participant consent if participants choose to use this method in place of written consent.

Questions or Further Information about the Project

Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

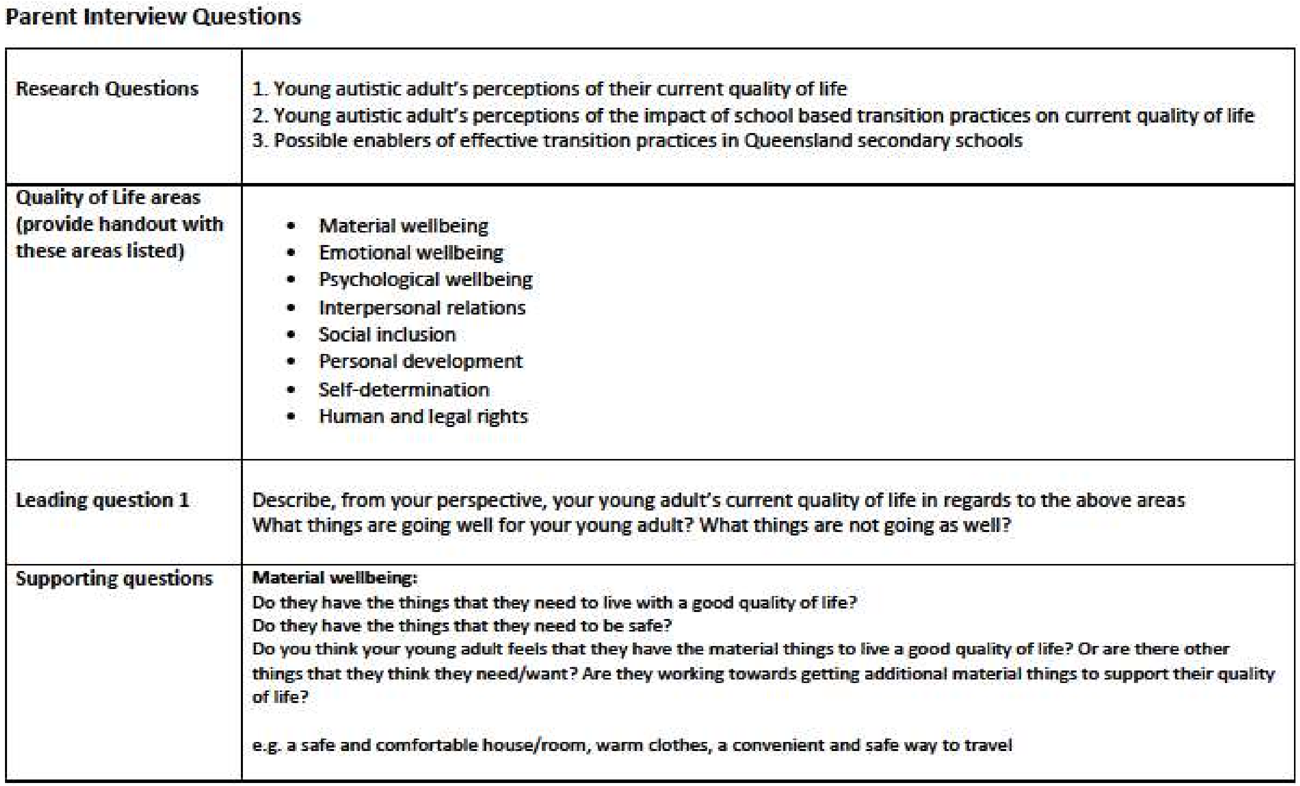
Concerns or Complaints Regarding the Conduct of the Project

If you have any concerns or complaints about the ethical conduct of the project you may contact the University of Southern Queensland Manager of Research Integrity and Ethics on +61 7 4631 2214 or email researchintegrity@usq.edu.au. The Manager of Research Integrity and Ethics is not connected with the research project and can facilitate a resolution to your concern in an unbiased manner.

Thank you for taking the time to help with this research project. Please keep this sheet for your information.

Appendix K

Parent Interview Questions



Parent Interview Questions

Research Questions	1. Young autistic adult's perceptions of their current quality of life 2. Young autistic adult's perceptions of the impact of school based transition practices on current quality of life 3. Possible enablers of effective transition practices in Queensland secondary schools
Quality of Life areas (provide handout with these areas listed)	• Material wellbeing • Emotional wellbeing • Psychological wellbeing • Interpersonal relations • Social inclusion • Personal development • Self-determination • Human and legal rights
Leading question 1	Describe, from your perspective, your young adult's current quality of life in regards to the above areas What things are going well for your young adult? What things are not going as well?
Supporting questions	**Material wellbeing:** Do they have the things that they need to live with a good quality of life? Do they have the things that they need to be safe? Do you think your young adult feels that they have the material things to live a good quality of life? Or are there other things that they think they need/want? Are they working towards getting additional material things to support their quality of life? e.g. a safe and comfortable house/room, warm clothes, a convenient and safe way to travel

	Emotional/psychological wellbeing: In general, how do you think your young adult's emotional/psychological health is? Do they experience any really difficult emotions that impact on their quality of life? How do you think your young adult would rate their own emotional/psychological wellbeing? Do they talk to you or others about emotional or psychological wellbeing? e.g. anxiety, stress, anger management issues **Interpersonal relations:** Does you young adult have a range of important people in their life? How does your young adult get on with the people in their life? Do you think they are happy with the range of people they have in their life or are there other relationships that they would like to have? e.g. Mum/Dad, siblings, friends, girlfriend/boyfriend, partner, children **Social inclusion:** What sorts of social things does your young adult do? Do they participate in social and/or community events? Do you think they are happy with their level of social inclusion, or are there other things they would like to be a part of? e.g. play sport, go out with friends, spend time with family, attend functions **Personal development** How has your young adult continued to learn and grow since leaving school? Are they moving ahead in terms of their personal development? Or are there areas where you think they would like to be able to learn or do more? e.g. New skills for work or to live independently, learning to drive a car, new sporting skills or hobbies, new social skills such as dating etc.

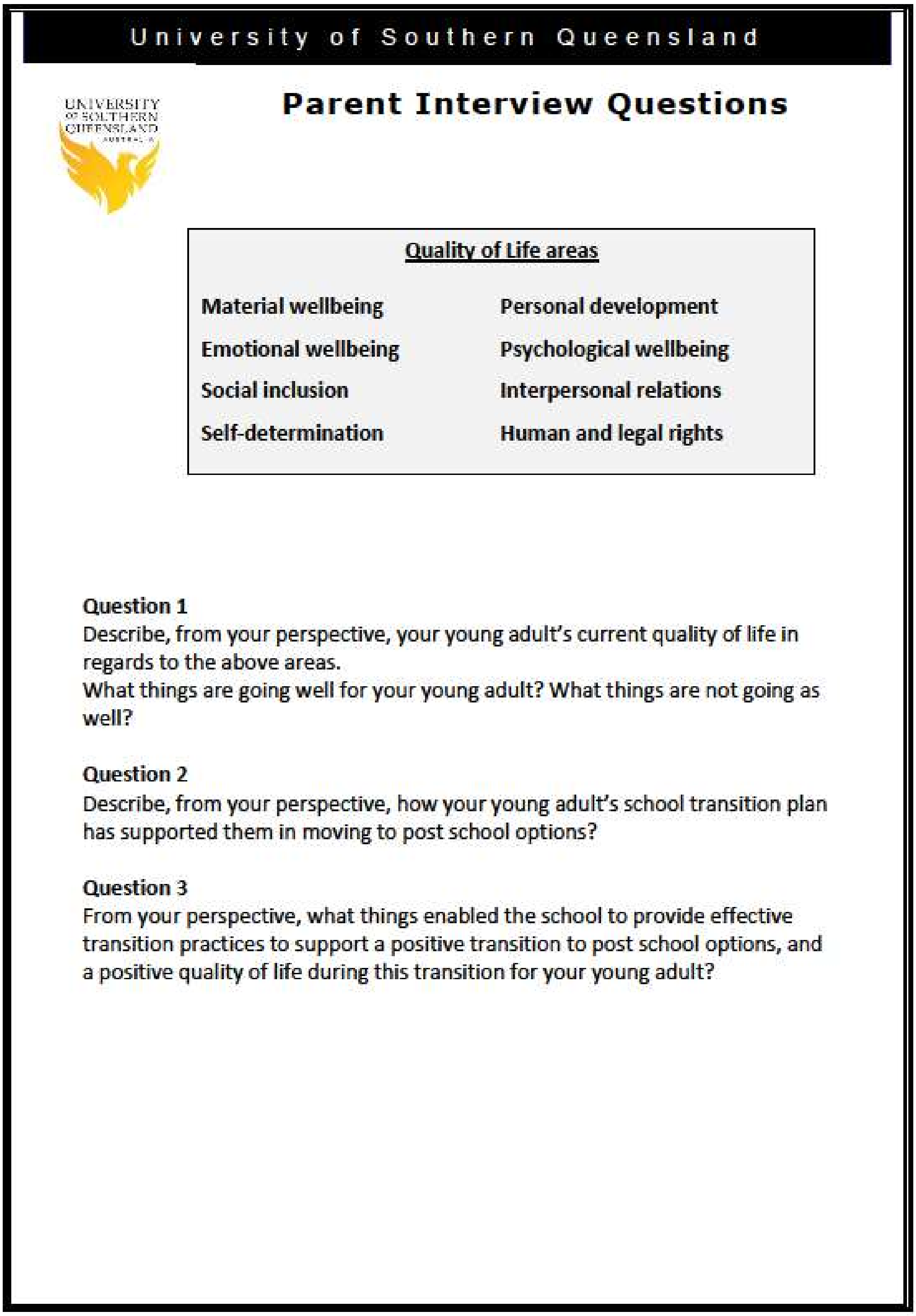
	Self-determination Does your young adult make decisions for themselves? If so, in what areas? Do you feel that that your young adult has the level of personal control that they want in life? Do you think they would want to make more or different decisions for themselves? If so, in what areas? Are there any factors that you think enable your young adult to make decisions for themselves? e.g. What they spend their time doing, what they spend their money on, who they spend their time with, where they live **Human and legal rights** Does your young adult experience the same human and legal rights as their non-autistic peers in the community? Are there areas where you think this is lacking? What supports does your young adult access to help them in this area? If something goes wrong, how would they go to for help? Would they know who to go to? e.g. what people support them and how, do they access community/government supports such as advocacy supports, employment support, financial support
Leading question 2	Describe from your perspective, how your young adult's school transition plan has supported them in moving to post school options?
Supporting questions	**Material wellbeing:** Did they learn how to budget Look after themselves (e.g. dress comfortably, plan healthy meals, keep their belongings safe/tidy) Did they participate in any programs that addressed this area? Did they have any specific support people who worked with them on this at school? Was this part of their transition plan? If not, do you feel it should have been? **Emotional/psychological wellbeing:** Did they learn how to manage their emotions/psychological wellbeing? Did they participate in any programs that addressed this area? Did they have any specific support people who worked with them on this at school? Was this part of their transition plan? If not, do you feel it should have been?

	Interpersonal relations: Did your young adult have a range of important people in their life at school? Did they have good relationships with people at school e.g. teachers, friends, parents etc. Did they learn how to manage relationships with others, or maintain good relationships? Did they participate in any programs that addressed this area? Did they have any specific support people who worked with them on this at school? Was this part of their transition plan? If not, do you feel it should have been? **Social inclusion:** What sorts of social activities did your young adult participate in at school? Do they participate in school social and/or community events? Do you think they were happy with their level of social inclusion at school, or were there other things they would have liked to be a part of? Did they participate in any programs that addressed this area? E.g. social skills programs Did they have any specific support people who worked with them on this at school? Was this part of their transition plan? If not, do you feel it should have been? **Personal development** What personal development areas was your young adult focused on at school? Were they able to move ahead in terms of their personal development? Were there areas where you think they would have liked to be able to learn or do more, or where you would have liked them to learn or be able to do more at school? Did they participate in any programs that addressed this area? Did they have any specific support people who worked with them on this at school? Was this part of their transition plan? If not, do you feel it should have been?

	Self-determination Was your young adult supported or taught how to make decisions for themselves at school? If so, in what areas? Do you think they would have liked to make more or different decisions for themselves at school? If so, in what areas? Did they participate in any programs that addressed this area? E.g. self-determination skills program Did they have any specific support people who worked with them on this at school? Was this part of their transition plan? If not, do you feel it should have been? **Human and legal rights** Did your young adult experience the same human and legal rights as their non-autistic peers at school? Were there areas where you think this was lacking? What do you think were the main areas? If something went wrong at school, who did they go to for help? Did they know who to go to? Did they/you receive supports to help them in this area? Did they participate in any programs that addressed this area? Did they have any specific support people who worked with them on this at school? Was this part of their transition plan? If not, do you feel it should have been?
Leading question 3	From your perspective, what things enabled the school to provide effective transition practices to support a positive transition to post school options, and a positive quality of life during this transition for your young adult?
Supporting questions	**Student focussed planning:** What sort of involvement did the young person have in the development of their transition plan in secondary school? What did this look like? What processes were followed to ensure that your child was able to be involved in this decision making process? **Student development** During secondary school, did the young person participate in activities/programs to increase their level of self-determination?

Appendix L

Parent Question Handout



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Parent Interview Questions

Quality of Life areas

- Material wellbeing
- Emotional wellbeing
- Social inclusion
- Self-determination
- Personal development
- Psychological wellbeing
- Interpersonal relations
- Human and legal rights

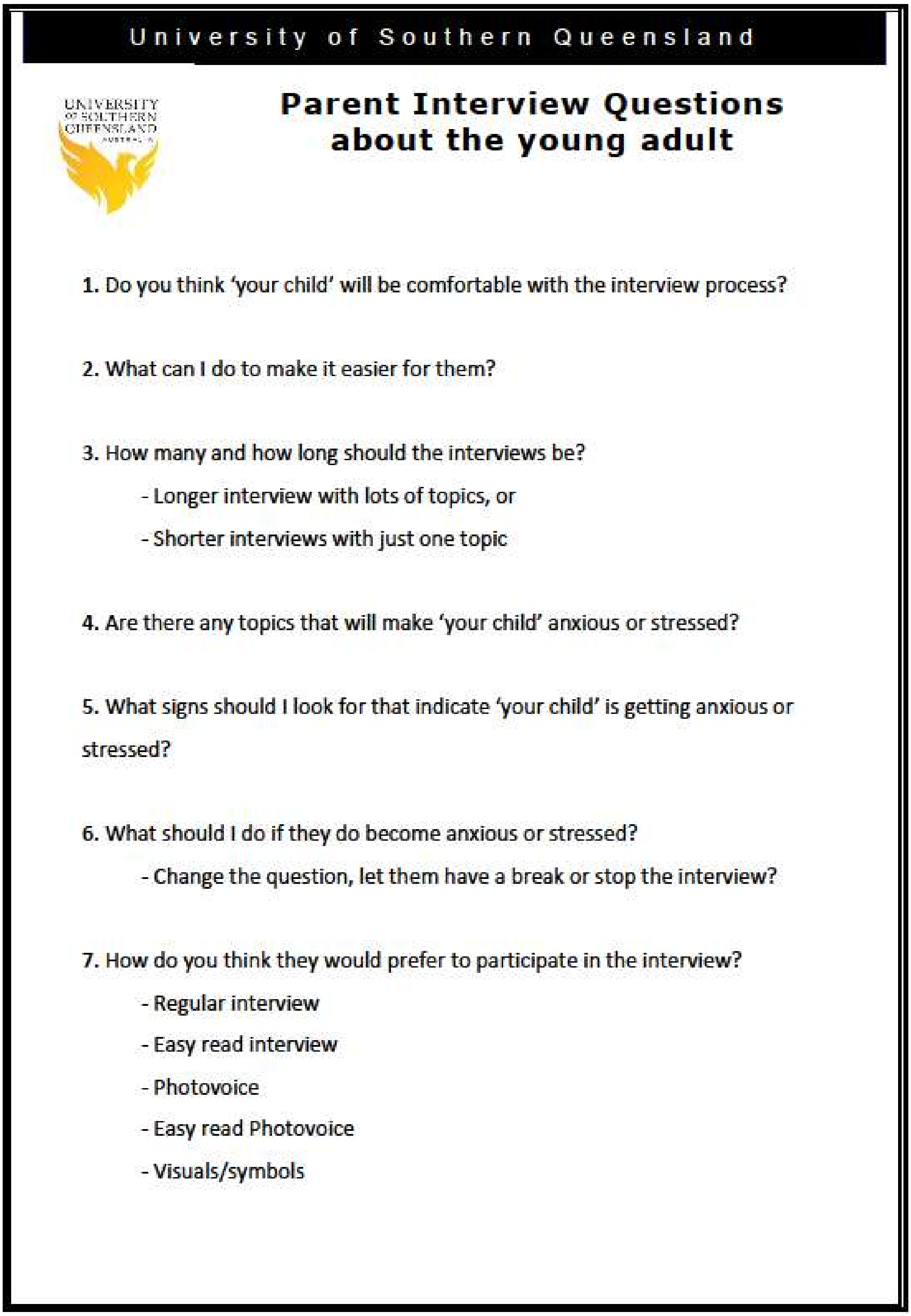
Question 1
Describe, from your perspective, your young adult's current quality of life in regards to the above areas.
What things are going well for your young adult? What things are not going as well?

Question 2
Describe, from your perspective, how your young adult's school transition plan has supported them in moving to post school options?

Question 3
From your perspective, what things enabled the school to provide effective transition practices to support a positive transition to post school options, and a positive quality of life during this transition for your young adult?

Appendix M

Parent Questions: About Participant



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UNIVERSITY OF SOUTHERN QUEENSLAND AUSTRALIA

Parent Interview Questions about the young adult

1. Do you think 'your child' will be comfortable with the interview process?

2. What can I do to make it easier for them?

3. How many and how long should the interviews be?
    - Longer interview with lots of topics, or
    - Shorter interviews with just one topic

4. Are there any topics that will make 'your child' anxious or stressed?

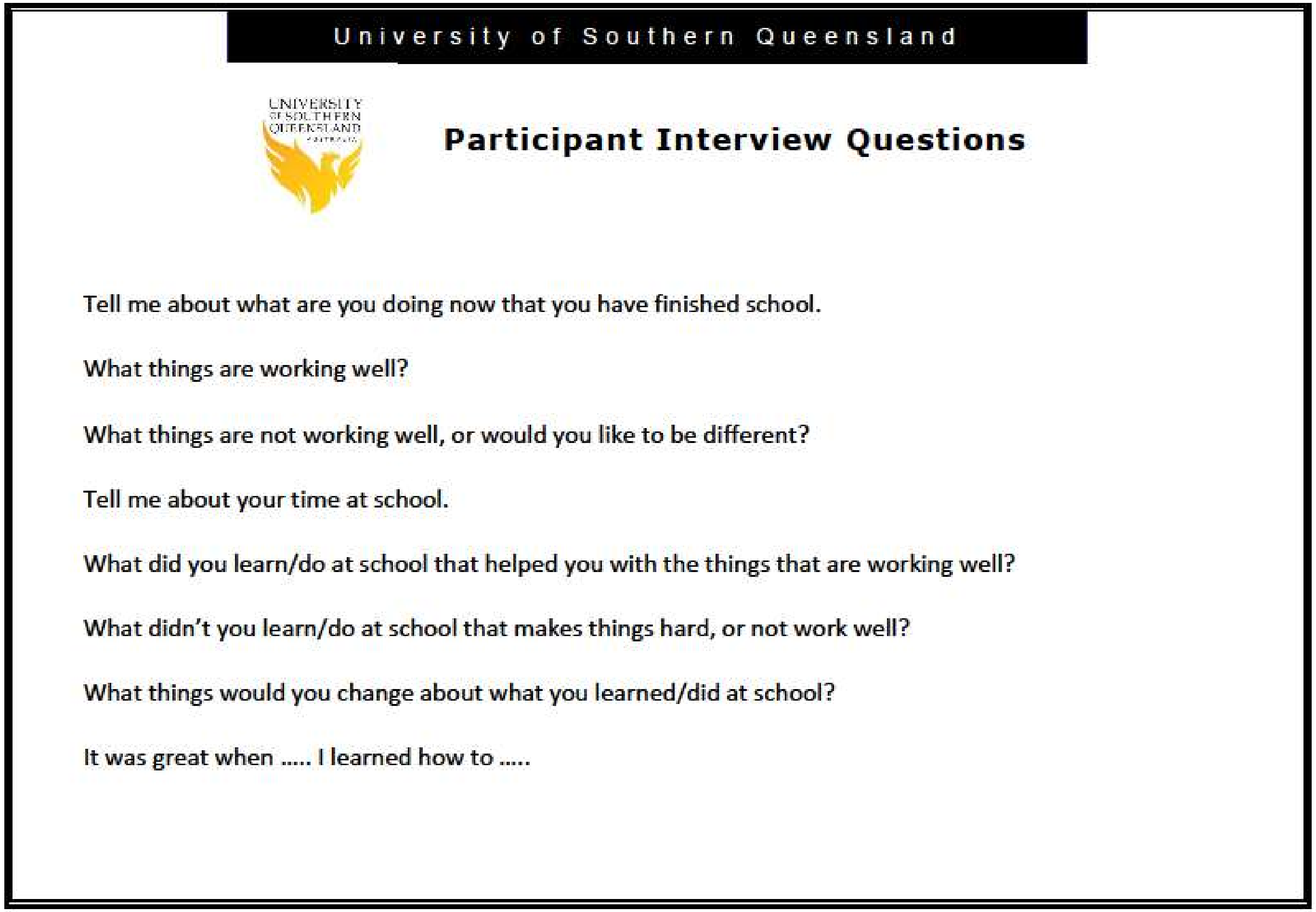
5. What signs should I look for that indicate 'your child' is getting anxious or stressed?

6. What should I do if they do become anxious or stressed?
    - Change the question, let them have a break or stop the interview?

7. How do you think they would prefer to participate in the interview?
    - Regular interview
    - Easy read interview
    - Photovoice
    - Easy read Photovoice
    - Visuals/symbols

Appendix N

Participant Questions



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Participant Interview Questions

Tell me about what are you doing now that you have finished school.

What things are working well?

What things are not working well, or would you like to be different?

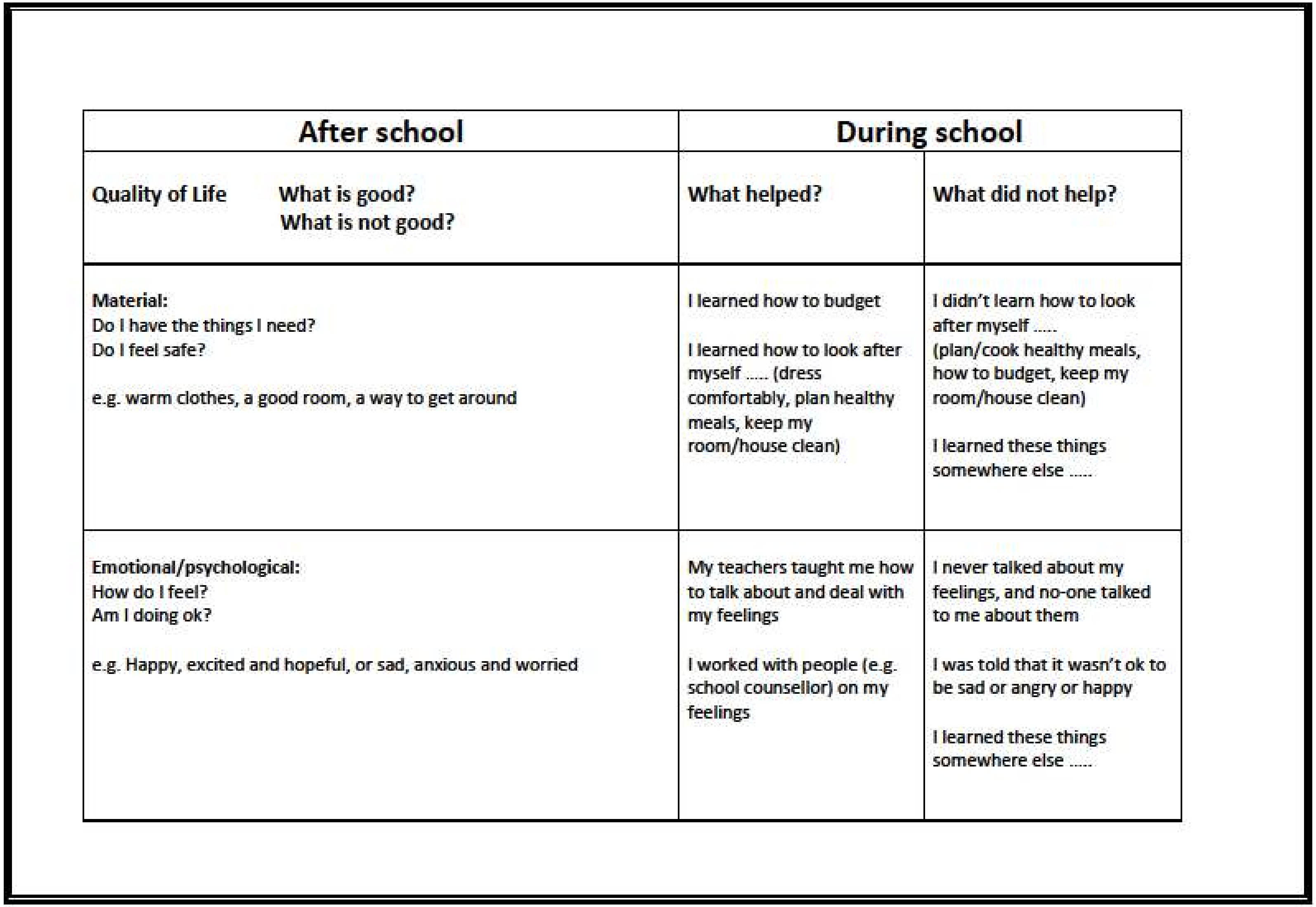
Tell me about your time at school.

What did you learn/do at school that helped you with the things that are working well?

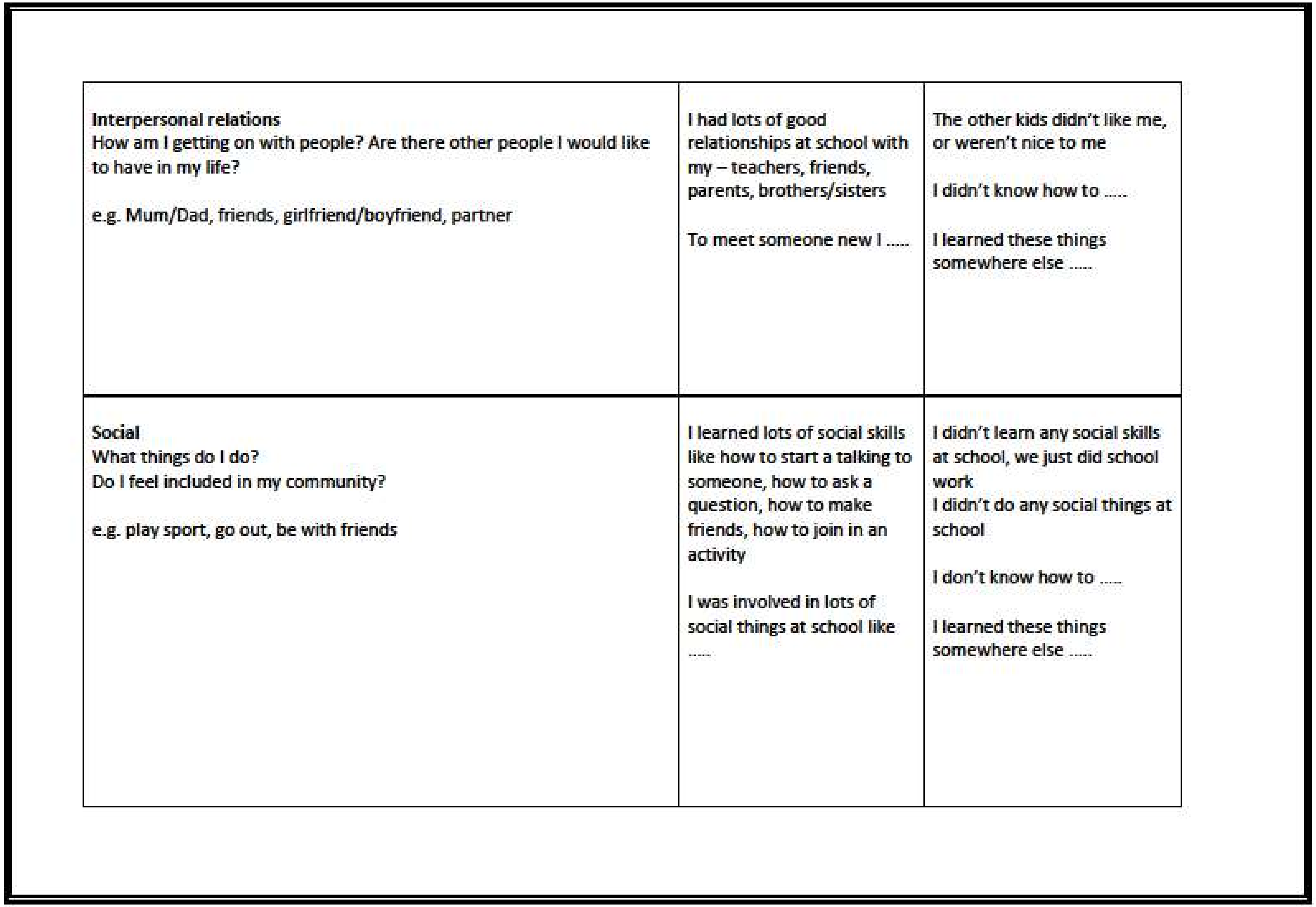
What didn't you learn/do at school that makes things hard, or not work well?

What things would you change about what you learned/did at school?

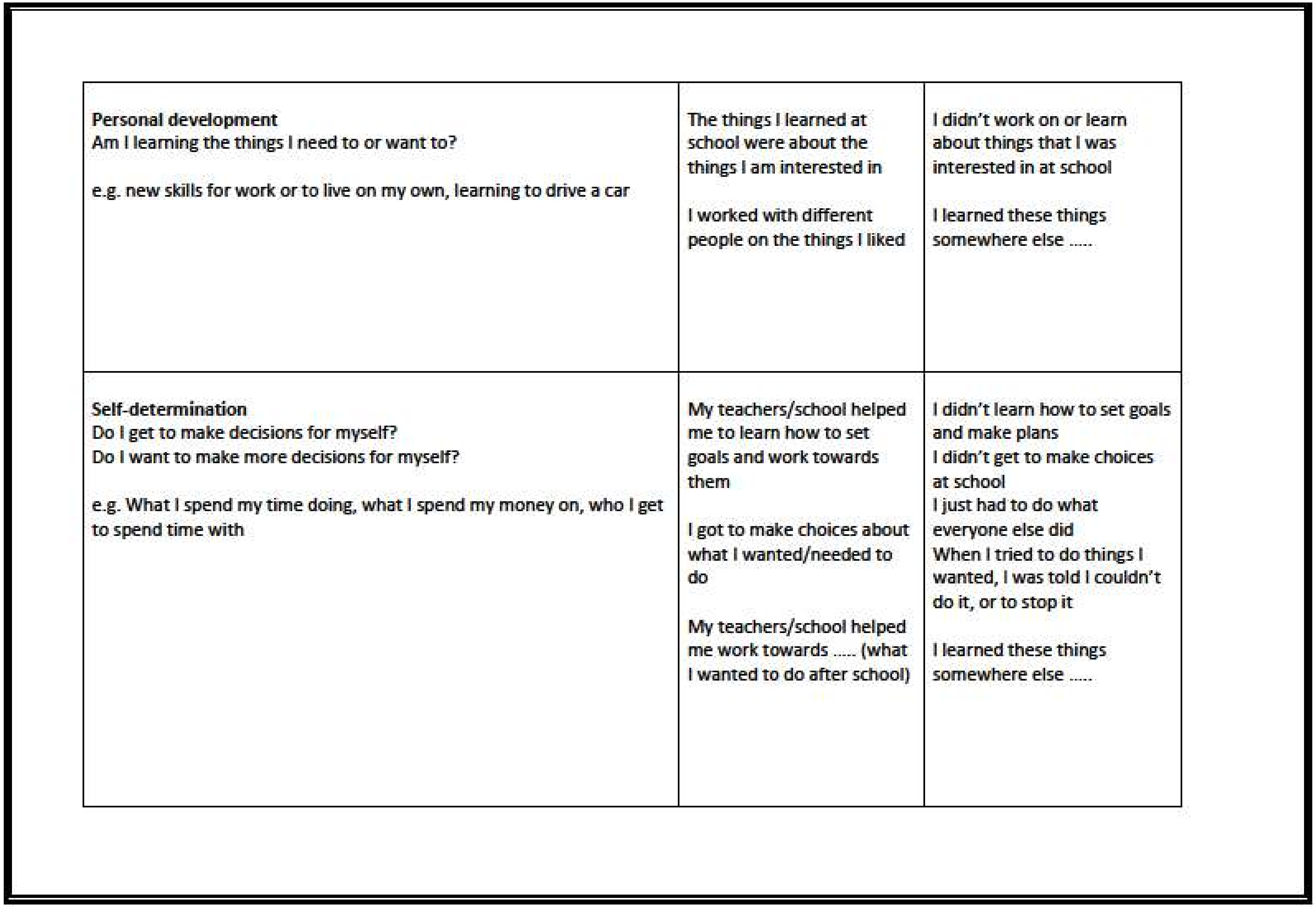
It was great when ..... I learned how to .....



After school	During school	
Quality of Life **What is good?** **What is not good?**	**What helped?**	**What did not help?**
Material: Do I have the things I need? Do I feel safe? e.g. warm clothes, a good room, a way to get around	I learned how to budget I learned how to look after myself ..... (dress comfortably, plan healthy meals, keep my room/house clean)	I didn't learn how to look after myself ..... (plan/cook healthy meals, how to budget, keep my room/house clean) I learned these things somewhere else .....
Emotional/psychological: How do I feel? Am I doing ok? e.g. Happy, excited and hopeful, or sad, anxious and worried	My teachers taught me how to talk about and deal with my feelings I worked with people (e.g. school counsellor) on my feelings	I never talked about my feelings, and no-one talked to me about them I was told that it wasn't ok to be sad or angry or happy I learned these things somewhere else .....



Interpersonal relations How am I getting on with people? Are there other people I would like to have in my life? e.g. Mum/Dad, friends, girlfriend/boyfriend, partner	I had lots of good relationships at school with my – teachers, friends, parents, brothers/sisters To meet someone new I …..	The other kids didn't like me, or weren't nice to me I didn't know how to ….. I learned these things somewhere else …..
Social What things do I do? Do I feel included in my community? e.g. play sport, go out, be with friends	I learned lots of social skills like how to start a talking to someone, how to ask a question, how to make friends, how to join in an activity I was involved in lots of social things at school like …..	I didn't learn any social skills at school, we just did school work I didn't do any social things at school I don't know how to ….. I learned these things somewhere else …..

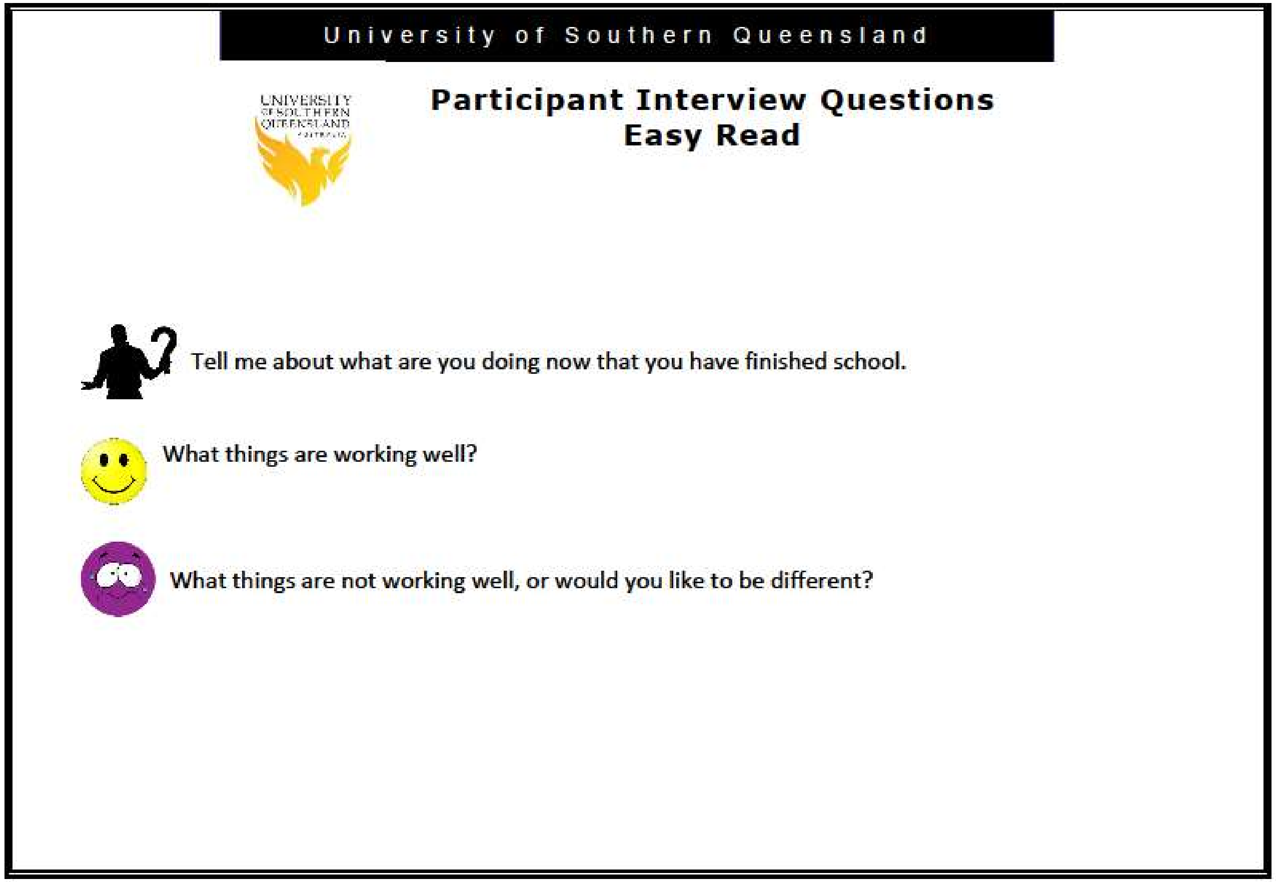


Personal development Am I learning the things I need to or want to? e.g. new skills for work or to live on my own, learning to drive a car	The things I learned at school were about the things I am interested in I worked with different people on the things I liked	I didn't work on or learn about things that I was interested in at school I learned these things somewhere else …..
Self-determination Do I get to make decisions for myself? Do I want to make more decisions for myself? e.g. What I spend my time doing, what I spend my money on, who I get to spend time with	My teachers/school helped me to learn how to set goals and work towards them I got to make choices about what I wanted/needed to do My teachers/school helped me work towards ….. (what I wanted to do after school)	I didn't learn how to set goals and make plans I didn't get to make choices at school I just had to do what everyone else did When I tried to do things I wanted, I was told I couldn't do it, or to stop it I learned these things somewhere else …..

Human and legal rights Do I feel included in my community? Do I get the help I need? e.g. What people support me and how? If something goes wrong – who can I go to	I felt like I belonged at my school I was always included If something wasn't working there was someone to help me work it out	I didn't feel like I belonged at my school I wasn't included in the things I wanted to be If something wasn't working, I didn't know who to go to/there was no one to go to

Appendix O

Participant Questions: Easy read



University of Southern Queensland

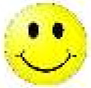
Participant Interview Questions
Easy Read

Tell me about what are you doing now that you have finished school.

What things are working well?

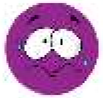
What things are not working well, or would you like to be different?

Tell me about your time at school.



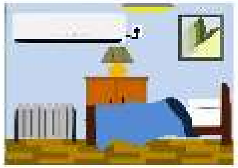
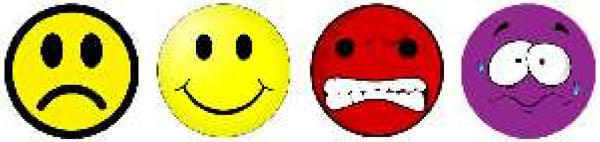
What did you learn/do at school that helped you with the things that are working well?

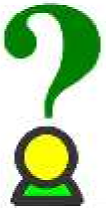
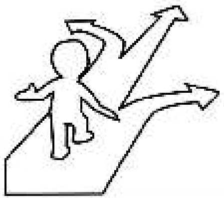
It was great when ….. I learned how to …..



What didn't you learn/do at school that makes things hard, or not work well?

What things would you change about what you learned/did at school?

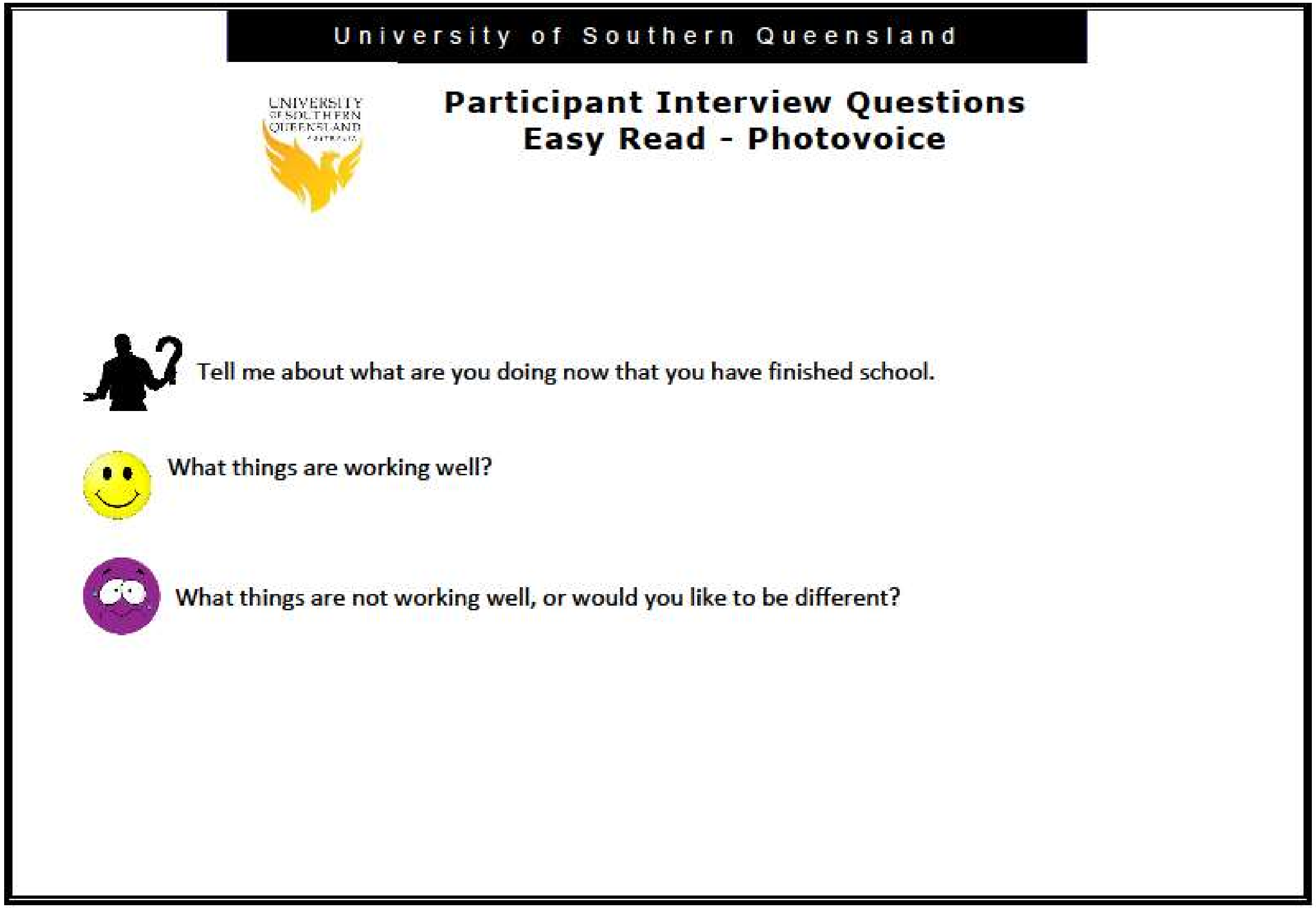
Quality of Life	Quality of Life
Material: Do I have the things I need? Do I feel safe? e.g. warm clothes, a good room, a way to get around	 
Emotional/psychological: How do I feel? Am I doing ok? e.g. anxiety, depression, excitement, hope	
Interpersonal relations How am I getting on with people? Are there other people I would like to have in my life? e.g. Mum/Dad, friends, girlfriend/boyfriend, partner	 

Social What things do I do? Do I feel included in my community? e.g. play sport, go out, be with friends	 
Personal development Am I learning the things I need to or want to? e.g. new skills for work or to live on my own, learning to drive a car	 
Self-determination Do I get to make decisions for myself? Do I want to make more decisions for myself? e.g. What I spend my time doing, what I spend my money on, who I get to spend time with	 

Human and legal rights Do I feel included in my community? Do I get the help I need? e.g. The people who support me? If something goes wrong – who can I go to?	 

Appendix P

Participant Questions: Photovoice



University of Southern Queensland

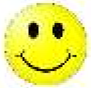
Participant Interview Questions
Easy Read - Photovoice

Tell me about what are you doing now that you have finished school.

What things are working well?

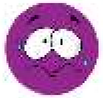
What things are not working well, or would you like to be different?

Tell me about your time at school.



What did you learn/do at school that helped you with the things that are working well?

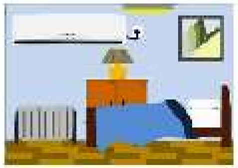
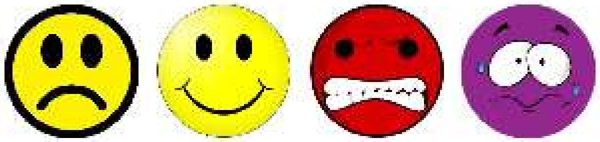
It was great when ….. I learned how to …..



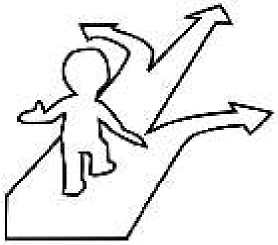
What didn't you learn/do at school that makes things hard, or not work well?

What things would you change about what you learned/did at school?

Take photos of:

Quality of Life	Quality of Life
Material: Do I have the things I need? Do I feel safe? e.g. warm clothes, a good room, a way to get around	 
Emotional/psychological: How do I feel? Am I doing ok? e.g. anxiety, depression, excitement, hope	

Interpersonal relations How am I getting on with people? Are there other people I would like to have in my life? e.g. Mum/Dad, friends, girlfriend/boyfriend, partner	 
Social What things do I do? Do I feel included in my community? e.g. play sport, go out, be with friends	 
Personal development Am I learning the things I need to or want to? e.g. new skills for work or to live on my own, learning to drive a car	 

Self-determination Do I get to make decisions for myself? Do I want to make more decisions for myself? e.g. What I spend my time doing, what I spend my money on, who I get to spend time with	 
Human and legal rights Do I feel included in my community? Do I get the help I need? e.g. The people who support me? If something goes wrong – who can I go to?	 

Appendix Q

Participant Information Table

Name	Age	Age at diagnosis	School attended	Currently lives	Comments
John	22 years	3 years	Regional city state high school	Regional city	Lives independently with his brother (who also has ASD) Works on a permanent part-time basis as a kitchen hand
Helen	22 years	14 years	Regional city state high school	Regional city	Lives with mum, dad and 2 sisters (all 3 girls have ASD diagnosis). Currently not working or studying. Planning to move overseas in the next 12 months.
Anne	18 years	10 years	Regional city state high school	Regional city	Lives with mum, dad and 2 sisters (all 3 girls have ASD diagnosis). Recently graduated high school About to start University study

					(Bachelor of Arts – History).
Eric	22 years	Self-diagnosed in recent years	Home schooled until year 9 Regional Christian school P - 12	Small coastal city	Currently living with mum and stepdad after living away from home to attend University - Bachelor of Physics Currently working part-time as a teacher aide, and Studying at postgraduate level - Masters of Learning and Teaching
Tamara	20 years	11 years	Small regional town Christian P – 12 school	Small regional town	Lives with mum, dad and 2 sisters. Was working in childcare but was recently let go. Currently looking for work at local childcare organisations
Frank	34 years	12 years	Regional city state high school	Satellite suburb of Regional city	Lives with Mum and stepdad Currently volunteering in a

					local aged-care facility
Piper	20 years	4 years		Metropolitan Christian school	Lives independently with her boyfriend. Currently studying a double degree in psychology and counselling and works part-time as a disability support carer. Piper and her mother were interviewed together.
Paul	38 years	Exact age unknown	Small regional town state high school	Small regional town	Lives with dad Mum passed away when Paul was very young Currently works casually making bee keeping boxes Has strong interest in meteorology and runs a local Facebook weather watcher’s group
Bruce	38 years	Exact age unknown	Small regional town state high school	Small regional town	Lives independently in a detached house on his parent’s property. Works part-time at

	the local bacon factory Helps his parents with running the farm.

Appendix R

Coding Strategy

Coding Strategy	When	How	Why
Attribute coding (For young adult)	Beginning	Based on attributes - age, gender, type of school attended, level of education, and location	Provide basic descriptive information about participants Parent attribute coding not required for this study as the parent's data is supportive only
In Vivo coding (For young adult)	First cycle coding	Using language of young adult	In vivo coding is used to prioritise and honour the participant's voice
Descriptive coding (For young adult and parent)	First cycle coding	Use of words or short phases to identify key substance of the data	Codes that are not In vivo codes To summarise key supporting (of young adults) points throughout parental data
Value coding (For young adult and parent)	First cycle coding	Use of + or – to attribute positive or negative occurrences	Coding used to identify participant's views on the use/or not of specific TT practices and/or the value placed on these practices AND QoL outcomes As above for parents

Provisional coding	Case specific	Moving first cycle In vivo codes into	Analysing first cycle coding in relation to connections between pre-determined coding categories from TTP and QoL frameworks to determine impacts for In vivo codes

Case specific Analysis	Research Question 1	NVivo exploration - Text searches - Crosstab analysis - Chart (+ versus -) Analysis of In vivo codes across QoL domains	Comparing + versus – QoL domains Determine overall QoL outcomes Link to self-determination theory and ASD Identification of ‘new’ factors in QoL domains?
Cross case analysis	Research Question 1	As above – cross case	Determine overall QoL outcomes across cases (positive versus negative QoL outcome domains) Link to self-determination theory and ASD Identification of ‘novel’ factors in QoL domains?

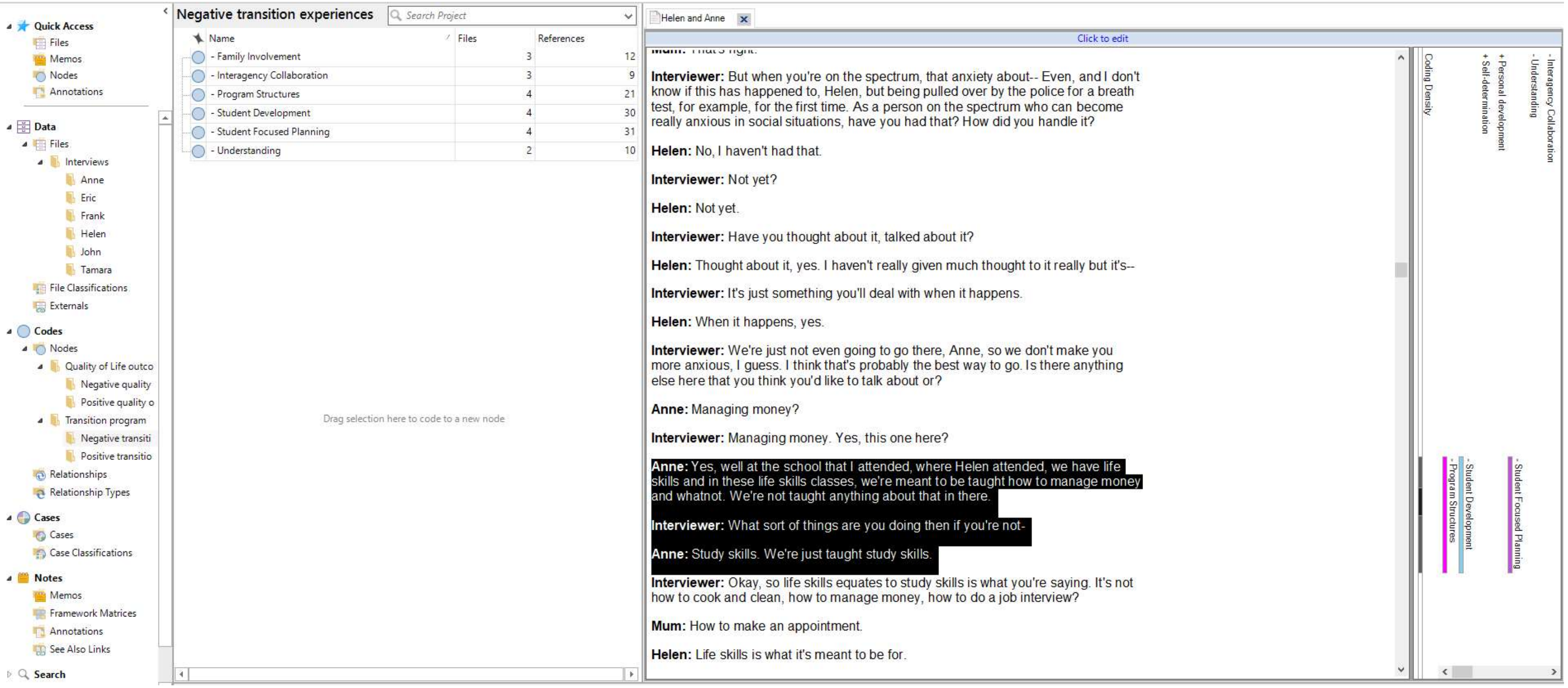
Case specific analysis	Research Question 2	NVivo exploration - Crosstab analysis - Network display (Conceptual framework relationships)	Comparison of TTP codes against QoL codes Identification of links between TTP and QoL Link to self-determination theory and ASD Identification of 'new' themes not addressed in either framework
Cross case analysis	Research Question 2	As above – cross case	Comparison of TTP codes against QoL codes Identification of links between TTP and QoL Link to self-determination theory and ASD
Case specific analysis	Research Question 3	- NVivo chart display - Network display (Conceptual framework)	Identification of key 'links/relationships' between TTP and QoL outcomes Identification of mediating factors associated with self-determination theory and ASD TTP and QoL
Cross case analysis	Research Question 3	As above – cross case	Identification of key 'links/relationships'

	between TTP and QoL outcomes (Strongest relationships = enablers) Identification of mediating factors associated Key links between self-determination theory and ASD TTP and QoL

Appendix S

Coding Example

Anne



Name	Files	References
- Family Involvement	3	12
- Interagency Collaboration	3	9
- Program Structures	4	21
- Student Development	4	30
- Student Focused Planning	4	31
- Understanding	2	10

Interviewer: But when you're on the spectrum, that anxiety about-- Even, and I don't know if this has happened to, Helen, but being pulled over by the police for a breath test, for example, for the first time. As a person on the spectrum who can become really anxious in social situations, have you had that? How did you handle it?

Helen: No, I haven't had that.

Interviewer: Not yet?

Helen: Not yet.

Interviewer: Have you thought about it, talked about it?

Helen: Thought about it, yes. I haven't really given much thought to it really but it's--

Interviewer: It's just something you'll deal with when it happens.

Helen: When it happens, yes.

Interviewer: We're just not even going to go there, Anne, so we don't make you more anxious, I guess. I think that's probably the best way to go. Is there anything else here that you think you'd like to talk about or?

Anne: Managing money?

Interviewer: Managing money. Yes, this one here?

Anne: Yes, well at the school that I attended, where Helen attended, we have life skills and in these life skills classes, we're meant to be taught how to manage money and whatnot. We're not taught anything about that in there.

Interviewer: What sort of things are you doing then if you're not-

Anne: Study skills. We're just taught study skills.

Interviewer: Okay, so life skills equates to study skills is what you're saying. It's not how to cook and clean, how to manage money, how to do a job interview?

Mum: How to make an appointment.

Helen: Life skills is what it's meant to be for.

Discussion of life skills classes. Anne states that ‘we have life skills and in these life skills classes, we’re meant to be taught how to manage money and whatnot. We’re not taught anything about that in there. She goes on to respond to the question about what they did in these classes, ‘Study skills. We’re just taught study skills.’

This was coded in the following way:

In vivo quote - ‘We’re just taught study skills’

Negative transition ‘Student development’ - because they are not taught life skills in life skills classes, so this is an example of not being offered appropriate student development. Not because it teaches them nothing, but because it doesn’t teach them what they are expecting to learn.

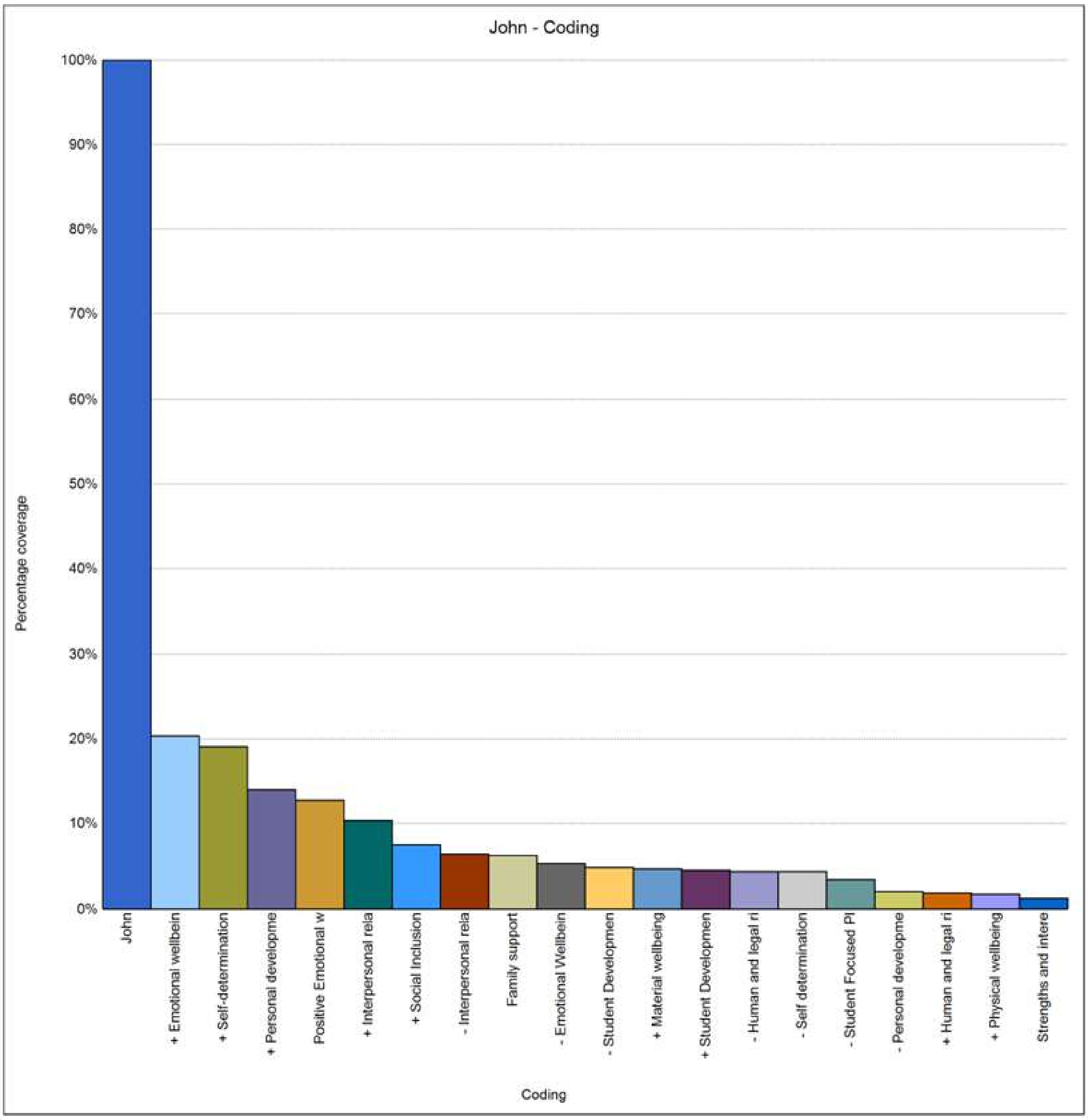
Negative transition ‘Program Structures’ – coded here because this is a negative example of program characteristics and resource development and allocation

Negative transition ‘Student-focused planning’ – coded here because this is an example of the students not being involved in what they are being taught, not being given the opportunity to share what skills they value and need to learn, and this being included in their program

Positive transition ‘Student development’ – coded here because the students were taught study skills

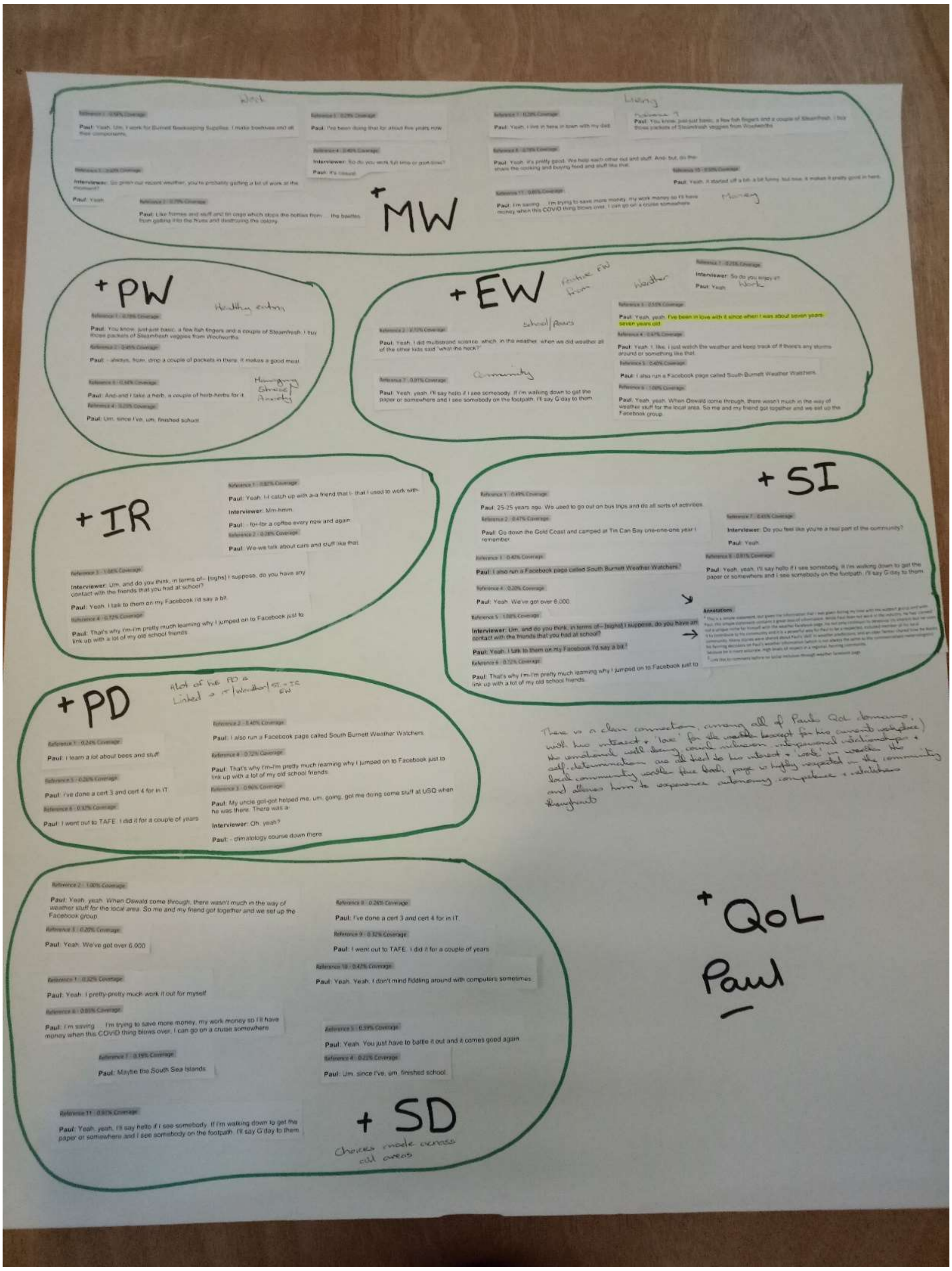
Appendix T

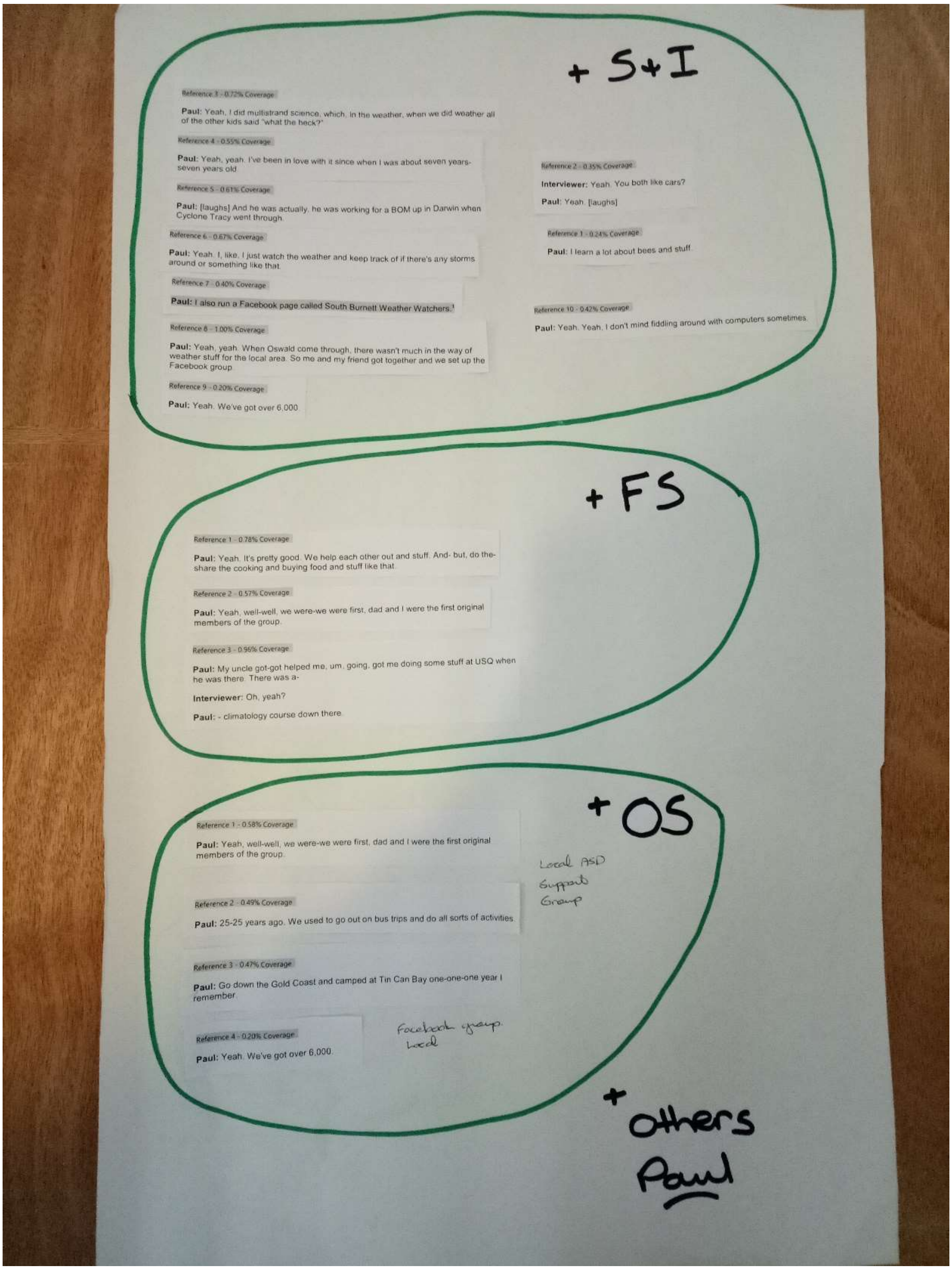
Coding Charts Example



Appendix U

Physical Coding Example





Reference 3 - 0.72% Coverage

Paul: Yeah, I did multistrand science, which, in the weather, when we did weather all of the other kids said "what the heck?"

Reference 4 - 0.55% Coverage

Paul: Yeah, yeah. I've been in love with it since when I was about seven years-seven years old.

Reference 5 - 0.61% Coverage

Paul: [laughs] And he was actually, he was working for a BOM up in Darwin when Cyclone Tracy went through.

Reference 6 - 0.67% Coverage

Paul: Yeah. I, like, I just watch the weather and keep track of if there's any storms around or something like that.

Reference 7 - 0.40% Coverage

Paul: I also run a Facebook page called South Burnett Weather Watchers.[1]

Reference 8 - 1.00% Coverage

Paul: Yeah, yeah. When Oswald come through, there wasn't much in the way of weather stuff for the local area. So me and my friend got together and we set up the Facebook group.

Reference 9 - 0.20% Coverage

Paul: Yeah. We've got over 6,000.

Reference 2 - 0.35% Coverage

Interviewer: Yeah. You both like cars?

Paul: Yeah. [laughs]

Reference 1 - 0.24% Coverage

Paul: I learn a lot about bees and stuff.

Reference 10 - 0.42% Coverage

Paul: Yeah. Yeah, I don't mind fiddling around with computers sometimes.

Reference 1 - 0.78% Coverage

Paul: Yeah. It's pretty good. We help each other out and stuff. And- but, do the-share the cooking and buying food and stuff like that.

Reference 2 - 0.57% Coverage

Paul: Yeah, well-well, we were-we were first, dad and I were the first original members of the group.

Reference 3 - 0.96% Coverage

Paul: My uncle got-got helped me, um, going, got me doing some stuff at USQ when he was there. There was a-

Interviewer: Oh, yeah?

Paul: - climatology course down there.

Reference 1 - 0.58% Coverage

Paul: Yeah, well-well, we were-we were first, dad and I were the first original members of the group.

Local ASD
Support
Group

Reference 2 - 0.49% Coverage

Paul: 25-25 years ago. We used to go out on bus trips and do all sorts of activities.

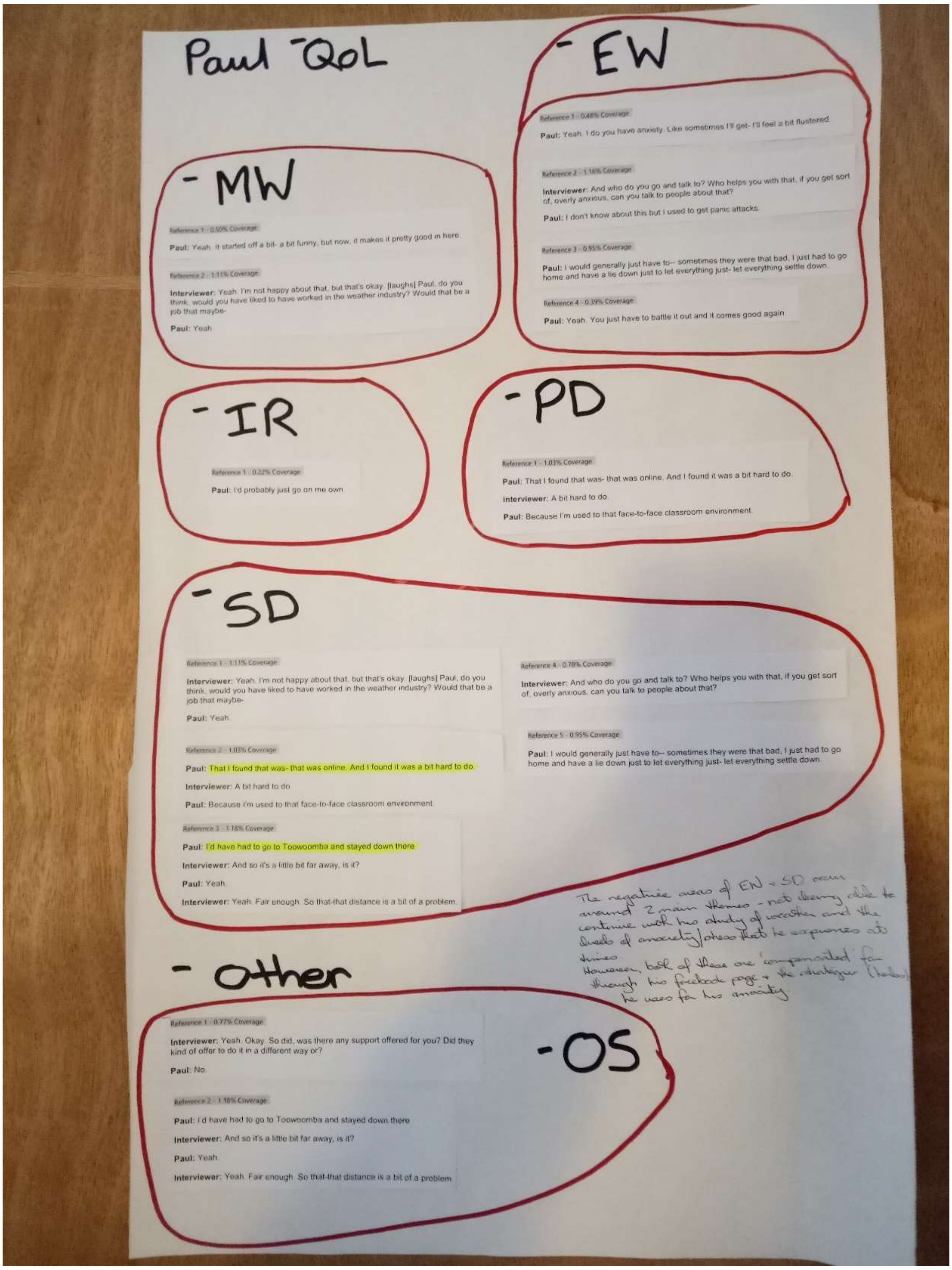
Reference 3 - 0.47% Coverage

Paul: Go down the Gold Coast and camped at Tin Can Bay one-one-one year I remember.

Reference 4 - 0.20% Coverage

Paul: Yeah. We've got over 6,000.

Facebook group.
Local



Paul QoL

- MW

Reference 1 - 0.50% Coverage

Paul: Yeah. It started off a bit- a bit funny, but now, it makes it pretty good in here.

Reference 2 - 1.11% Coverage

Interviewer: Yeah. I'm not happy about that, but that's okay. [laughs] Paul, do you think, would you have liked to have worked in the weather industry? Would that be a job that maybe-

Paul: Yeah

- EW

Reference 1 - 0.48% Coverage

Paul: Yeah. I do you have anxiety. Like sometimes I'll get- I'll feel a bit flustered.

Reference 2 - 1.16% Coverage

Interviewer: And who do you go and talk to? Who helps you with that, if you get sort of, overly anxious, can you talk to people about that?

Paul: I don't know about this but I used to get panic attacks.

Reference 3 - 0.95% Coverage

Paul: I would generally just have to-- sometimes they were that bad, I just had to go home and have a lie down just to let everything just- let everything settle down.

Reference 4 - 0.39% Coverage

Paul: Yeah. You just have to battle it out and it comes good again.

- IR

Reference 1 - 0.22% Coverage

Paul: I'd probably just go on me own.

- PD

Reference 1 - 1.03% Coverage

Paul: That I found that was- that was online. And I found it was a bit hard to do.

Interviewer: A bit hard to do.

Paul: Because I'm used to that face-to-face classroom environment.

- SD

Reference 1 - 1.11% Coverage

Interviewer: Yeah. I'm not happy about that, but that's okay. [laughs] Paul, do you think, would you have liked to have worked in the weather industry? Would that be a job that maybe-

Paul: Yeah.

Reference 2 - 1.03% Coverage

Paul: That I found that was- that was online. And I found it was a bit hard to do.

Interviewer: A bit hard to do.

Paul: Because I'm used to that face-to-face classroom environment.

Reference 3 - 1.18% Coverage

Paul: I'd have had to go to Toowoomba and stayed down there.

Interviewer: And so it's a little bit far away, is it?

Paul: Yeah.

Interviewer: Yeah. Fair enough. So that-that distance is a bit of a problem.

Reference 4 - 0.78% Coverage

Interviewer: And who do you go and talk to? Who helps you with that, if you get sort of, overly anxious, can you talk to people about that?

Reference 5 - 0.95% Coverage

Paul: I would generally just have to-- sometimes they were that bad, I just had to go home and have a lie down just to let everything just- let everything settle down.

The negative areas of EW + SD occur around 2 main themes - not being able to continue with his study of weather and the levels of anxiety/stress that he experiences at times.
However, both of these are 'compensated' for through his facebook page + the strategies ([illegible]) he uses for his anxiety

- other

- OS

Reference 1 - 0.77% Coverage

Interviewer: Yeah. Okay. So did, was there any support offered for you? Did they kind of offer to do it in a different way or?

Paul: No.

Reference 2 - 1.18% Coverage

Paul: I'd have had to go to Toowoomba and stayed down there

Interviewer: And so it's a little bit far away, is it?

Paul: Yeah.

Interviewer: Yeah. Fair enough. So that-that distance is a bit of a problem