TRANSITION EXPERIENCES OF YOUNG ADULTS ON THE AUTISM SPECTRUM IN AUSTRALIA: A MIXED-METHODS ANALYSIS

A Thesis submitted by

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Abstract

The shift from high school to adulthood encompasses adult responsibilities in employment, post-secondary education, independent living, and overall good social relationships recognised as traditional demographic markers of a successful transition and better quality of life. Navigating these adult roles and responsibilities are associated with increased independence that requires adjusting to new settings. As difficulty coping with change is a hallmark of Autism Spectrum Disorder, the normative challenges and change associated with the transition to adulthood are compounded with multiple difficulties unique to an Autism Spectrum Disorder diagnosis.

Over the last decade, Australia has seen an increase in the number of children and adolescents diagnosed with Autism Spectrum Disorder. The implication for the future is that there would be an increase in the number of young adults on the autism spectrum requiring adult support services and interventions. Within an ecological systems perspective, young adults on the autism spectrum interact with family, school, and support systems as they transition to adulthood. A systems analysis therefore provided a holistic perspective of the successes and challenges during the transition period first hand from key stakeholders. As such, the overall aim of the present program of research was to implement a mixed-methods design to explore the barriers and facilitators to a successful transition to adulthood for young adults on the autism spectrum in Australia.

Collectively, qualitative findings from Study 1 and Study 2 highlighted five main themes of *Embracing ASD Differences*, *Social Interaction*, *Functional Independence*, *Support experiences*, and *Employment* as areas of importance associated with successful and unsuccessful transition. A longitudinal case series analysis in Study 3 extended the qualitative findings from Study 1 and Study 2 and provided further evidence for the role of risk and protective factors during the transition period. Targeted transition planning and interventions, parental involvement in transition planning, work experience placements, and support from service providers appeared to be protective factors for those young adults who experienced a successful transition. Lower functional independence, co-occurring depression and anxiety, limited social skills, and communication challenges emerged as risk factors. Finally, Study 4 provided a comprehensive insight of successes and challenges within current Australian disability infrastructure from the perspectives of support providers. Success in support provision included effective communication and Autism Spectrum Disorder specific knowledge. Challenges included organisational influences of school systems and service provider infrastructure.

The first unique contribution of this thesis is to provide key insider perspectives towards the implementation of a specialist Autism Spectrum Disorder model of support within the National Disability Insurance Scheme. Second, the awareness of a *strengths* and *abilities* perspective at a systemic level is necessary to embrace a shift from a *deficit* and *impairment* lens towards the inclusion of young adults on the autism spectrum in all aspects of adult and community life. Finally, this program of research extends the current literature on risk and protective factors during the transition period. Collectively, understanding the range of outcomes for the young adult population on the autism spectrum, and their parents' perceptions is of significance to key stakeholders in tailoring service delivery to meet the unique needs of these individuals.

Keywords: Autism spectrum disorder, transition, adulthood, quality of life

Certification of Thesis

This Thesis is entirely the work of Yosheen Pillay except where otherwise acknowledged. The work is original and has not previously been submitted for any other award, except where acknowledged.

Yosheen Pillay 27/02/2018

Principal Supervisor: Associate Professor Charlotte Brownlow

Associate Supervisor: Associate Professor Sonja March

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

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List of Conference Presentations

Pillay, Y. (June, 2017). *Service providers: Transition perspectives in their own voices*. Paper presentation at the Critical Autism Studies Conference, London.

Pillay, Y. (April, 2016). *Workplace transitions for adolescents with autism spectrum disorder*. Paper presentation at the Pacific Rim International Conference on Disability and Diversity, Hawaii.

Pillay, Y. (October, 2016). *Teacher voices of transitions for adolescents with autism spectrum disorder: An interpretative phenomenological analysis*. Paper presentation at Autism Spectrum Australia Conference, Autism in Education, Melbourne, Australia.

Pillay, Y. (April, 2015). *Lived experiences of transitions*. Paper presentation at Asia Pacific Conference Autism and Transitions, Brisbane, Australia.

List of Publications

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Chapter 1 - Introduction

The shift from high school to adulthood is a challenging developmental progression as all young people face opportunities and challenges that would shape their futures (Carter, Brock, & Trainor, 2014). For young adults on the autism spectrum specifically, the defining traits of an Autism Spectrum Disorder (ASD) diagnosis further hamper the transition process. Transition indicates a shift in role status for young adults aged 18 to 25 years, from the primary position of an adolescent to undertaking initial adult responsibilities within society (Arnett, 2014). Although timelines cannot be exactly defined, young adulthood is conceptualised as a developmental bridge between adolescence (13 to17 years) and early adulthood (17 to 45 years) and recognises the ages of 18 to 25 years as a transition phase of young adults into early adulthood (Arnett, 2014; Levinson, 1986). This introductory chapter will present the rationale for the present program of research and provide a broad understanding of ASD and factors that underpin the transition to adulthood for young adults on the autism spectrum. The significance and purpose of the research, study aims and research questions, research plan, and structure of the thesis will also be presented. Finally, the rationale for using a mixed-methods research design and associated methodology will be discussed in detail.

Research Rationale

For many young adults, the transition to adulthood is fraught with hope and uncertainty as they face normative adult challenges of autonomy, post-secondary education, and career choices (Cobb, 2006; Santrock, 2005; Zanden, 2003). Increased independence, social interactions, establishing and building relationships, independent living, and intimacy are new and challenging roles for all young adults (Geller & Greenberg, 2009). Taken together, the transition to adulthood is recognised as a stressful period for parents of young adults on the autism spectrum, and presents increased risk for young adults themselves as they face a loss of school support structure, change in disability service entitlements, and a shift in social role position (Smith & Anderson, 2014; Taylor & Mailick, 2014). In particular, difficulty coping with change is a hallmark of ASD, therefore, for young adults on the autism spectrum the normative challenges and change associated with the transition to adulthood are compounded with multiple difficulties unique to ASD.

An analysis of the literature recognises the period of high school completion, post-secondary education, the initial years of employment, functional independence, integrating with the community, and overall good personal and social relationships as traditional demographic markers of a successful transition to adulthood and good quality of life (QOL: Hendricks & Wehman, 2009; Wehman, 2006). There are some trends observed in the literature on different perspectives of roles and responsibilities for young adults within the age group of 18 to 25 that differ from normative social roles and expectations traditionally associated with a successful transition to adulthood. One such proposition is emerging adulthood conceptualised as a period of extended role exploration and identity formation where individuals do not necessary enter and settle into long-term adult roles (Arnett, 2014). Arnett (2014) refers to demographic changes in industrialised countries in delayed age of marriage and parenthood, the rise of gender equality, and increased post-secondary education as some factors influencing the nature of development from the late teens to early twenties for some individuals within this transition period. However, not all individuals in this age group experience prolonged transitions as emerging adults.

Terms of Reference

Historically, according to the Social Model of Disability (Thomas, 2004) being disabled has been associated with social exclusion and stigma, and has rarely functioned as a socially inclusive practice. However, emerging discourse in current research suggests a need to focus on the positive aspects of individuals on the autism spectrum from an abilities perspective (Grandin & Panek, 2013). Qualitatively, it is noted that *impairment* and *deficit* infers a negative connotation, as such, throughout this thesis, reference will be made to *differences* and *challenges* faced by young adults on the autism spectrum. Terminology has been controversial with tensions between person first and identity first language. In order to achieve balance and adopt an *abilities* framework within this thesis, individuals with an ASD diagnosis will be referred to as individuals on the autism spectrum, and the term neurotypical will be used to refer to non-autistic peers following Kenny et al. (2015). Since the focus of this thesis is on young adults and the period of transition, it is necessary at times to include knowledge of adolescents and the period of adolescence whilst talking about individuals prior to the transition to adulthood. Therefore, within this thesis, reference is sometimes made to adolescent populations where specifically mentioned by researchers in the literature presented.

What is Autism Spectrum Disorder?

The *Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition* (DSM-5: American Psychiatric Association [APA], 2013) defines ASD as a dyad of developmental difficulties evident by a narrow, repetitive pattern of behaviours activities and interests, as well as differences in social communication and social interaction. According to the DSM-5 (APA, 2013) the diagnosis of ASD encompasses diagnoses previously referred to as Autistic disorder, Asperger syndrome, Childhood Disintegrative Disorder or Pervasive Developmental Disorder Not Otherwise Specified.

Individuals on the autism spectrum experience variability in social functioning and communication ability with each person demonstrating different strengths and challenges (Autism Spectrum Australia [ASPECT], 2013). As such, ASD is conceptualised as existing along a continuum of severity from mild to severe. ASD is associated with intellectual disability (ID) and approximately 50% of individuals on the autism spectrum have an intellectual ability within the average to above average range (i.e., IQ above 85; APA, 2013; Centers for Disease Control and Prevention, 2014). Due to changes in the DSM-5 (APA, 2013) diagnostic criteria the reference to average to above average intellectual ability within this program of research encompasses previous diagnoses of Asperger Syndrome and the more general label of high functioning autism, that is, individuals with an IQ greater than 85 without ID (APA, 2013; Centers for Disease Control and Prevention, 2014).

Historically, much of the research has focused on individuals with severe forms of ASD and co-occurring ID, with even fewer studies exploring outcomes of adults on the autism spectrum without co-occurring ID (Farley et al., 2009; VanBergeijk, Klin, & Volkmar, 2008). Recent research by Magiati, Tay, and Howlin (2014) found great variability in outcomes in the population of adults on the autism spectrum without co-occurring ID. It may be that with different support, training, and education, some individuals on the autism spectrum without co-occurring ID can be successful in educational achievement, employment, and independent living. Whilst such individuals are sometimes referred to as having a mild form of ASD, they still require autism-specific support and interventions. Thus, the objective of the present program of research is to explore barriers and facilitators during the journey to adulthood in the population of young adults on the autism spectrum without the associated difficulties of an ID. In doing so, it is posited that their individual experiences will provide a roadmap of areas requiring targeted intervention to facilitate the inclusion of a productive and functioning young adult within the community. Therefore, the population of focus within this program of research are young adults on the autism spectrum within average or above average intellectual ability.

Due to ASD associated challenges including difficulty in social interaction and communication, the majority of young adults on the autism spectrum continue to experience challenges in education, employment, independent living, friendships, and romantic relationships throughout their adult lives (Billstedt, Gillberg, & Gillberg, 2007; Farley et al., 2009; Howlin, Goode, Hutton, & Rutter, 2004; Marriage, Wolverton, & Marriage, 2009). In addition, many young adults on the autism spectrum experience secondary characteristics of sensory sensitivities, and mental health issues such as depression and anxiety (Attwood, 2008; Ozsivadjian, Hibberd, & Hollocks, 2014; White, Oswald, Ollendick, & Scahill, 2009). Sensory sensitivities may be experienced in response to noise, fluorescent lighting, textures, smells, and tastes including hypersensitivity to any of the senses (Attwood, 2008). Research suggests that because individuals on the autism spectrum within average to above average intellectual ability are more able than individuals with other disabilities, they experience distress by their social incapacities, and are susceptible to anxiety, depression, and low self-esteem (White et al., 2009). For instance, it is suggested that anxiety occurs because these individuals are cognisant of their difficulty in social interactions, that depression occurs because of the stigma linked to coping with social difficulties, and collectively, that low self-esteem emerges because these individuals are aware of a combination of these difficulties (Attwood, 2008; Bellini, 2006; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Hillier, Fish, Siegel, & Beversdorf, 2011; White et al., 2009). Therefore, young adults on the autism spectrum transitioning to adult roles and responsibilities may find the transition period exceptionally difficult.

Significance of Autism Spectrum Disorder. In recent years, Australia has seen an increase in the number of individuals diagnosed with an ASD (Australian Bureau of Statistics [ABS], 2012). This is of significant concern with 1 in 160 children diagnosed in 2006, to 1 in 63 children diagnosed in 2012, approximately an increase of 15% per year (ABS, 2012; Autism Asperger's Advocacy Australia, 2012; Buckley, 2009; MacDermott, Williams, Ridley, Glasson, & Wray, 2006). With regards to adolescents, recent research indicates that ASD is estimated to affect 1 in 52 Australian adolescents aged 13 to 15 years old, with an overall increase of 42% in the number of Australians on the autism spectrum since 2012 (Autism Asperger's Advocacy Australia, 2015; ABS, 2016). According to the ABS (2016) it is likely that changes to the DSM-1V (APA, 2000) diagnostic criteria and an increased awareness of ASD over time may have influenced the increase in prevalence, particularly in the age group under 25. Collectively therefore, the increase in ASD prevalence across both children and adolescents in Australia would suggest an influx in the number of individuals on the autism spectrum requiring support as young adults.

According to the ABS (2016) only 40 % of individuals on the autism spectrum accessed employment compared to 53% of individuals with a disability, and 83% of individuals without a disability. The unemployment rate reported for individuals on the autism spectrum was more than three times the rate for individuals with a disability and almost six times the rate for individuals without a disability (ABS, 2016). The greatest challenges in general were in the area of communication, where 51% of individuals reported having difficulty being understood or in understanding what others were saying. Further, 63% of difficulties reported in education settings were fitting in socially, 62% with learning difficulties, and 51% related to communication challenges (ABS, 2016). Thus, the outcomes for the young adult population on the autism spectrum are generally poor. Notably, intermingled within these reported overall poor outcomes may be a subgroup of young adults who are potentially capable of achieving success in adulthood. However, little is known about what their specific needs might be due to limited Australian research with the young adult population on the autism spectrum (ASPECT, 2013; Beamish, Meadows, & Davies, 2012; Meadows et al., 2006; Neary, Gilmore, & Ashburner, 2015).

There is evidence that most individuals on the autism spectrum require a lifetime of support (Howlin & Moss, 2012). A recent review found the estimated annual cost of ASD in Australia between $8.1 billion and $11.2 billion (Synergies Economic Consulting, 2011). The most significant impact was in reduced income due to low employment rates for both families and individuals on the autism spectrum, and a high dependency on their families. Indeed, families play a pivotal role as caregivers, in decision-making, and are key stakeholders in advocating for support for their children on the autism spectrum (Pfeiffer, Piller, Giazzoni-Fialko, & Chainani, 2017). Of note, when compared to families of individuals with other disabilities, families of children on the autism spectrum experience increased difficulties in access to support services, with higher financial needs. In addition, families, more specifically mothers, are more likely to reduce their workload or even stop working due to meeting the support needs of their children on the autism spectrum (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Kogan et al., 2008; Lord & Bishop, 2010). In particular, recent data from the ABS (2016) indicates that the most common support for 84% of individuals on the autism spectrum was informal care provided by mothers. As such, it is important to also consider family experiences of the transition to adulthood, to inform targeted support and interventions for the needs of families and individuals on the autism spectrum, and to contribute to research and knowledge in this area.

In sum, the overall poor adult outcomes, financial impact on family, society, and the work force, suggest a need to investigate factors that would facilitate a successful transition to adulthood for these individuals, to alleviate a dependency on family, the state welfare system, and improve overall QOL. Of note, young adults on the autism spectrum interact with family, school, and support systems as they transition to adulthood, therefore, Bronfenbrenner's Ecological Systems Theory (1994) provides a suitable framework through which to explore the transition to adulthood, across family, school, community, and government support systems, and will be discussed in detail in Chapter 2.

At present, the Australian disability support system is embracing a new infrastructure in the National Disability Insurance Scheme (NDIS). This change in disability support structure presents a pivotal opportunity for key stakeholders, government, and disability policy developers to identify and improve previous areas overlooked, specifically in the realm of identification and targeted intervention for young adults on the autism spectrum (Australian Advisory Board on ASD, 2011). Taken together, with the increase in prevalence and growing awareness of ASD, it is imperative that service providers have an in-depth understanding of ASD as a lifelong developmental condition, requiring ongoing individualised support. Further, in contributing ASD specific knowledge to NDIS infrastructure, the present program of research aims to highlight the transition journey first hand from young adults on the autism spectrum in Australia, parents of young adults on the autism spectrum, and disability service providers.

Aims and Research Questions

A diagram of the research design including the overall research aim and different methods used for each study are shown in the flowchart (see Figure 1.1).

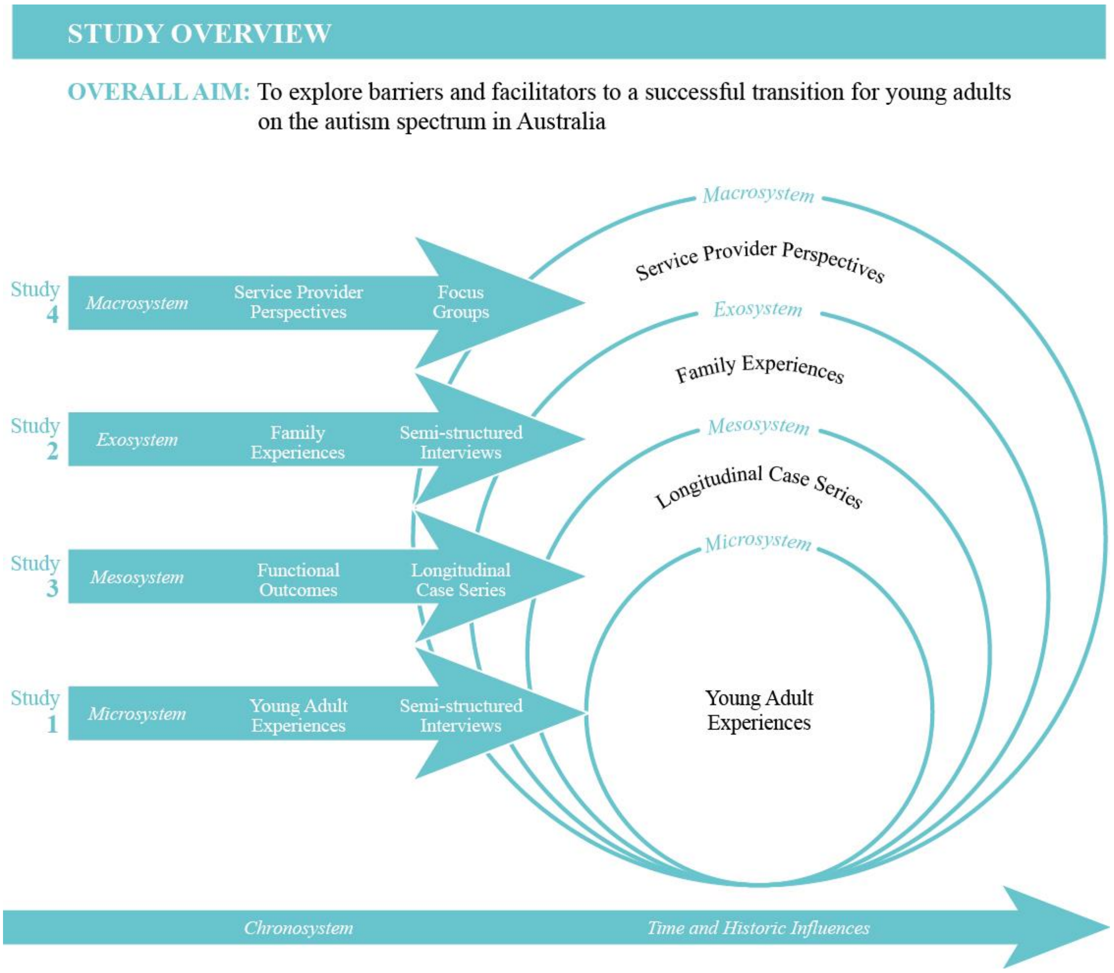


Figure 1.1. Flowchart of research design with four studies mapped onto Bronfenbrenner's Ecological Model (1994).

The overall aim of this thesis is to identify barriers and facilitators to a successful transition to adulthood for young adults on the autism spectrum in Australia. Following the review of the literature in Chapter 2, each chapter will begin with a flowchart to contextualise the present program of research mapped onto

Bronfenbrenner’s Ecological Model (1994). Study 1 and Study 2 are qualitative and were conducted concurrently. The aim of Study 1 is to provide young adults on the autism spectrum with an opportunity to voice their transition experiences, to learn first hand and to capture the complexities and challenges of transitions, as well as to inform Study 3. As such, the research question that will guide Study 1 is: *What are the experiences of young adults on the autism spectrum during the transition to adulthood?* Qualitative methods using semi-structured interviews with a small sample of young adults on the autism spectrum provide a meaningful starting point to explore this research question. More specifically, semi-structured interviews will provide young adults and parents with the flexibility and choice to focus on issues that are meaningful to them.

The aim of Study 2 is to provide parents of young adults on the autism spectrum with an opportunity to voice their perspectives of the transition experience, to learn first hand and to capture their successes and challenges during transitions, as well as to inform Study 3. The following research question will guide Study 2: *What are the experiences of parents of young adults on the autism spectrum during the transition to adulthood?* Qualitative approaches have the capacity to explore complex issues, such as parent perspectives on the transition to adulthood (Cridland, Jones, Caputi, & Magee, 2015). As such, semi-structured interviews are guided by parent perceptions and experiences as is relevant to the aims of the present research (Cridland et al., 2015). Notably, parents are key stakeholders in the lives of their young adult children, and often report feeling excluded from support and planning processes (Beamish et al., 2012). Thus, further exploration of parent experiences will provide an insight into positive and negative interactions at both personal and community levels of interaction.

Study 3 will build upon the key findings from Study 1 and Study 2 to further assess factors that impact successful transition to adulthood in a quantitative pilot longitudinal case series study. Therefore, the aim of Study 3 is to further examine the qualitative outcomes of Study 1 and Study 2 in-depth over time. The research question that will guide Study 3 is: *What factors are evident during the transition period that might be related to a successful or unsuccessful transition to adulthood?* Longitudinal studies provide an opportunity to examine the transition process over a period of one year, and to determine what factors might be associated with successful or unsuccessful transition over time. Thus, Study 3 will use the qualitative findings from young adult and parent interviews to inform the development of a survey to assess for potential risk and protective factors associated with successful or unsuccessful transition. In this way, Study 3 will enhance and elaborate on the qualitative findings from Study 1 and Study 2.

The aim of study 4 is to provide a comprehensive overview of factors associated with success and challenges during the transition process, from the perspective of disability support providers. The research question that will guide Study 4 is: *What are the successes and challenges during the transition to adulthood for young adults on the autism spectrum from the perspectives of service providers?* Effective support for young adults on the autism spectrum requires a team approach, of which disability service providers are a core component (Carter et al., 2014; Davies & Beamish, 2009; Hendricks & Wehman, 2009; Trach, 2012). Within a holistic perspective, service provider experiences together with both young adults and families are pivotal to gaining a comprehensive understanding of perceived barriers and facilitators to a successful transition for individuals on the autism spectrum.

Thus, service provider perspectives will provide a valuable and comprehensive understanding of the current Australian disability service provision in Study 4.

Outline of the Research Design

The overall aim of the current program of research was to explore barriers and facilitators to a successful transition for young adults on the autism spectrum in Australia. Figure 1.1 illustrates the methodology employed in the four studies that include both qualitative and quantitative approaches. Therefore, this program of research uses a mixed-methods design, based on an exploratory sequential design (Creswell, 2007; Creswell & Plano Clark, 2011). In this thesis, qualitative methods are suited as an initial approach to exploring participants' experiences, beliefs, and meanings attributed to the transition phenomenon, and to convey multiple perspectives in Study 1 and Study 2 (Creswell & Plano Clark, 2011; Willig, 2013). Thereafter, quantitative methods are used sequentially in Study 3, to further examine the key qualitative findings from Study 1 and Study 2. Collectively, a mixed-methods design was chosen as the types of research questions that addressed specific issues in each of the four studies required different designs (Creswell & Plano Clark, 2011). In addition, a combination of both qualitative and quantitative methods extends the understanding of the overall research aim of this thesis, that is, to explore barriers and facilitators to a successful transition for young adults on the autism spectrum in Australia.

Semi-structured interviews in Study 1 and Study 2 position participants as experts in their transition journey and provide an insight as to how individuals interpret and order their world (Brocki & Weardon, 2006; Milena, Dainora, & Alin, 2008). Therefore, in the exploratory sequential design, the qualitative findings from Study 1 and Study 2 are used to inform the development of the quantitative survey for

Study 3 (Creswell, 2009; Creswell & Plano Clark, 2011). This mixed-methods approach allows for an initial understanding of the transition journey, by asking young adults of their transition experiences in Study 1, followed by parent experiences in Study 2. Thereafter, the qualitative findings from Study 1 and Study 2 are used for further examination of risk and protective factors associated with successful transition over time in a quantitative longitudinal case series study (Creswell & Plano Clark, 2011).

A major criticism of qualitative research is the lack of researcher rigour in data collection, analysis, and trustworthiness (Trainor & Graue, 2014). As such, several quality criteria have been implemented in this program of research to describe, interpret, and contextualise the transition journey. The different methodological approaches present credibility in methodological triangulation, that is, in capturing and acknowledging multiple perspectives, as to how young adults experience the transition journey (Lincoln & Guba, 1986). Indeed, Schalock (2004) suggests triangulation and methodological pluralism in conducting both qualitative and quantitative studies when exploring QOL with individuals with disability. In this mixed-methods thesis, qualitative analyses include Interpretative Phenomenological Analysis (IPA: Smith, Flowers, & Larkin, 2009) in Study 1 (Chapter 3) and Study 2 (Chapter 4), and thematic analysis in Study 4 (Chapter 6). For ease of readability and clarity across Study 1 and Study 2, IPA qualitative methodology and associated philosophical approaches are now discussed.

Qualitative Methodology

Phenomenology. According to Husserl (1927/1970) phenomenology is a philosophical approach to understanding the experience of a specific phenomenon, in this thesis the transition process. The life-world provides a framework within which the context of the transition experience can be understood. As such, individual experiences of transition phenomena are subjective in that their perceptions are influenced by their thoughts, beliefs, and expectations, and are reflective of what they conceive as reality at that point in time (Willig, 2013). In order to fully understand the transition experience, it is suggested that the researcher's assumptions, preconceptions, and judgements about the transition phenomenon is set aside, referred to, as bracketing. Moreover, Husserl (1927/1970) asserts that through the cyclical process of describing and reflecting on individual experiences, the researcher conducts a reduction, or different ways of thinking, and reasoning, about the transition process, thus capturing the essence of the phenomenon. Therefore, the process of systematic description and reflection lends itself to the theory of interpretation which Heidegger (1962/1927) refers to as hermeneutics. The specific phenomenological approach relevant to IPA methodology within this thesis is hermeneutic phenomenology (Porter & Cohen, 2013).

Hermeneutic Phenomenology. According to Heidegger (1962/1927) the theory of interpretation is based on phenomenology and is used to determine how people interpret their lives and make meaning of their experiences. Bracketing is addressed through a reflexive stance, as part of the tapestry in which interpretation takes place, and is situated within the researcher's own perspective and historical context (Cohen, Kahn, & Steeves, 2000). Indeed, it is suggested that assumptions and beliefs about the transition phenomenon are presented early in writing in order to stimulate a process of critical thinking and reflecting about the transition phenomenon. Therefore, the combined underpinnings of phenomenology and hermeneutics make IPA a suitable qualitative approach to analyse semi-structured interviews in Study 1 and Study 2.

Individuals on the autism spectrum often have unique insights about their specific situation, about what works for them, and what doesn’t. Therefore, providing an opportunity to listen to their voices empowers such individuals to talk about their lived experiences on issues that concern them directly (WHO, 2011). More specifically, in exploring young adult and parent experiences of the transition journey, a phenomenological approach in Study 1 and Study 2 provided participants with the opportunity to control and share their experiences first hand, and to converse with a purpose, specific aspects of the transition process of significance to them.

Interpretative Phenomenological Analysis. IPA is a qualitative approach that aims to gain an understanding of an individual’s perception and lived experience of a particular event (Smith et al., 2009). IPA has its philosophical origins in phenomenology that posits individuals experience the world within a specific context and a particular time (Willig, 2013). The transition to adulthood is largely a multifaceted phenomenon involving interaction between personal, social, and environmental factors. Given that the aim of Study 1 was to explore transition experiences by listening to the voices of young adults on the autism spectrum, and the aim of Study 2 was to explore transition experiences by listening to the voices of parents, IPA was deemed an appropriate research methodology.

IPA is particularly suited to understanding the chain of connection between the embodied experience, socio-emotional reaction, and sense making of the transition process through the lens of young adults on the autism spectrum and parents of young adults on the autism spectrum. As such, the psychological focus and personal meaningfulness of the transition process will vary depending on individual, family, and socio-cultural contexts.

Role of the Researcher. IPA is an interpretative endeavour. The IPA researcher’s aim is to gain a better insight of the individual’s psychological world by examining how the experience is structured in time, space, and social relationships to capture the essence (Willig, 2013). The IPA researcher has a dual role of engaging with and interpreting participants’ personal accounts to gain an insight of the individual’s psychological world (Brocki & Wearden, 2006). IPA asserts that the researcher is making sense of the participant making sense of the world, known as a double hermeneutic (Willig, 2013). Analysis and findings in IPA are therefore interpretative in that it is a culmination of participants’ views of the world as well as the researcher’s contributions.

A controversial aspect to qualitative research is the concept of *Epoché* (Willig, 2013). In IPA, bracketing of researcher fore-conceptions is addressed in a comprehensive reflexivity section. Prior knowledge and understanding of transition processes and the psychological construct of ASD is indeed necessary to make meaning of young adult, parent, and service provider experiences (Willig, 2013). The position of the researcher as co-author is embraced as some pre-existing knowledge and experience is indeed necessary (Morrow, 2005; Pringle, Drummond, McClafferty, & Hendry, 2011). Whilst the researcher has the freedom to be creative, a reflexive stance is necessary to reflect on personal values, experiences, beliefs, and interests that impact on the final analysis, contributing to the knowledge that shapes the research. Purposive conversations with my supervisors allowed me to reflect on the fore-structure of my personal experiences and assumptions of ASD and transitions, and record them as a personal checkpoint as data analysis commenced. It was therefore critical for me as a participatory analyst to reflect on and proclaim my contextual and cultural lens in a comprehensive reflexivity section (Smith et al., 2009).

Reflexivity. I have been a disability advisor in education for most of my teaching career. Throughout my research journey, I endeavoured to stay close to participants' experiences as a naïve enquirer. I remained cognisant of my inherent closeness with the data and navigated a conscious separateness during interactions with participants. As such, I engaged in regular reflective conversations with my supervisors and peer researchers on a similar topic to ensure my credibility in approaching all aspects of the research through a transparent cultural lens. I have aimed to remain grounded in analysing each experience, but accede that my reflections and sense making of the participants making sense of the transition process, is my hermeneutic circle, presented in this study.

Thesis Structure

The present introductory chapter, Chapter 1, provides a rationale for the body of research and presents a broad understanding of ASD. Chapter 2 will present a review of the literature on ASD and associated contexts within the transition to adulthood. Chapter 3 will report the findings from Study 1 which is qualitative in nature and used semi-structured interviews to explore Research Question 1: *What are the experiences of young adults on the autism spectrum during the transition to adulthood?* Chapter 4 will report the findings from Study 2, which is qualitative in nature and used semi-structured interviews to explore Research Question 2: *What are the experiences of parents of young adults on the autism spectrum during the transition to adulthood?*

Chapter 5 will report the findings from Study 3 which is a pilot longitudinal quantitative case series that used a survey to investigate Research Question 3: *What factors are evident during the transition period that might be related to a successful or unsuccessful transition to adulthood?* Chapter 6 will report the findings of Study 4 which is a qualitative study that used focus groups to explore Research Question 4: *What are the successes and challenges during the transition to adulthood for young adults on the autism spectrum from the perspectives of service providers?*

Chapter 7 will present a general discussion of the main findings of the four studies, and contributions of each study to the overall aim of the present body of research, which is: *What are the barriers and facilitators of a successful transition to adulthood for young adults on the autism spectrum in Australia?* Chapter 7 will also address the implications of the study findings, unique contribution to knowledge, strengths and limitations, key recommendations and suggestions for future research directions. Lastly, Chapter 7 concludes by returning to the rationale for the research, and the belief that effective support in the transition period is situated in gaining an understanding of individual experiences through their lens.

Summary

This introductory chapter provided a rationale for the overall body of research and presented a broad understanding of ASD. It also presented the main terms of reference used within this thesis. Thereafter, the study aims, research questions, and outline of the mixed-method research design were presented. Lastly, IPA qualitative methodology was discussed followed by a detailed outline of the thesis structure. The next chapter will discuss Bronfenbrenner's Ecological Systems Theory (1994) that underpins the four studies within this thesis, followed by a review of the literature on ASD and associated contexts within the transition to adulthood.

Chapter 2 - Review of the Literature

Traditional demographic markers of transition to adult roles, as identified in the literature, of independent living, friendships, post-secondary education, employment, and quality of life (QOL) are guiding constructs that underpin the four studies in this thesis (Hendricks & Wehman, 2009; Wehman, 2006). As the present program of research includes three distinct research participant groups, that is, young adults, parents, and service providers, the following clarifies how participants are referred to throughout this thesis. Young adults are referred to as such, but may also be referred to as young adult children within the context of family, or as students within the context of school and post-secondary education, and as clients in interactions with service providers. Parents may also be referred to as caregivers or advocates.

The aim of this literature review was to investigate and critique current and relevant existing literature from a global and Australian perspective, specifically on how transition to adulthood is conceptualised for young adults on the autism spectrum within average to above average intellectual ability. The literature reviewed is organised and approached in different ways throughout this thesis. First, given the three distinct groups of research participants, that is, young, adults, parents, and service providers, literature pertaining to participant roles, responsibilities, and transition experiences are discussed in detail. Second, as identified in the literature, focused areas of transition in independent living, social interaction, post-secondary education, employment, and QOL provide a guiding framework for the review of the literature. Finally, a critique of Australian research on young adults on the autism spectrum and the transition to adulthood specifically is narrated throughout the review of the literature.

This chapter will first discuss the theoretical framework that underpins the four studies in the present body of research, Ecological Systems Theory (EST: Bronfenbrenner, 1994) followed by a review of the literature of transitions from high school to experiences of post-secondary education, employment, living circumstances, social relationships and interactions, and QOL for young adults on the autism spectrum. Gaps identified in the literature and the significance of the study will conclude this review of the literature.

Ecological Systems Theory

The theoretical framework underpinning this program of research study is Bronfenbrenner's Ecological Model (1994). In his EST (Bronfenbrenner, 1994), Bronfenbrenner conceptualises human development from an interactionist perspective as a relationship between people and the different parts of the environment in which people interact. In this context, EST also includes a systems perspective in which different parts of the system affect each other. An important characteristic of EST is the focus on the development of individuals, which occurs across a number of systems. Indeed, during the transition to adulthood, the developing young adult interacts across different settings, such as family, school, community, post-secondary education, and employment settings. An ecological perspective acknowledges the interplay between an individual and the environment and has been applied to research in individuals with developmental disabilities and ID (see for example Schalock, Keith, Verdugo, & Gomez, 2010). As the transition to adulthood occurs within and across several settings, EST therefore provides a suitable framework to explore the transition to adulthood, within the context of the immediate environment of the young person, as well as interactions with the different systems in which the young adult interacts.

Bronfenbrenner’s EST (1994) defines five socially organised systems within the environment, each having an influence on the young person’s development. According to the ecological model, each of the systems is nested within each other, with the developing young person at the centre. The microsystem is the layer closest to the individual and encompasses relationships and interactions the young person has with the immediate environment. These include interactions with family, school, and the community. In Study 1, the microsystem provides the framework to explore the interrelationships of the young adult with family, school, and community during the transition to adulthood.

The exosystem defines the larger social system that may include one or more settings that the young person does not experience directly, however, structures within the exosystem may impact the young person’s development. In Study 2, the exosystem provides the framework to explore the interrelationships of family and their experiences across systems such as schools and transition planning, community support, post-school activities, and interactions with disability support services.

The mesosystem is the interrelationship between two or more microsystems or settings in which the developing young person is involved and includes the relationship between family experiences, school experiences, post-school opportunities, community access, and support experiences. In Study 3, access to transition support at high school, disability support post high school, employment, post-secondary education, and community integration that facilitates social belonging are factors that are intrinsically linked to the mesosystem and impact the young adult directly.

The macrosystem involves the cultural context, and includes societal values and belief systems, cultural norms, and policies or laws that directly influence the developing young person. In Study 4, the macrosystem provides the framework to explore service provider perspectives on socio-cultural factors such as disability infrastructure and evidence-based transition processes situated within current disability policies.

The overarching system of EST is the chronosystem that encompasses transitional changes over time for the developing young adult. Within this program of research, aspects of the chronosystem are interwoven across young adult experiences, within parent perspectives of interactions with various microsystems, longitudinally over time in young adult perspectives on their QOL and perceived social support, and across service provider experiences within the framework of disability policy.

Bronfenbrenner’s Ecological Model (1994) has shown to be useful in Australian research examining school transition processes for students with disabilities (Strnadová & Cumming, 2014), carer and teacher perspectives in transition support for students with disabilities (Strnadová, Cumming, & Danker, 2016), and the implementation of individual disability funding support packages (Laragy & Ottmann, 2011). Bronfenbrenner’s Ecological Model (1994) therefore, provides a lens that is relevant to view the transition to adulthood, from the experiences of young adults themselves, experiences of parents, and perspectives of service providers who support young adults on the autism spectrum. Figure 2.1 presents a visual representation of Bronfenbrenner’s Ecological Model (1994).

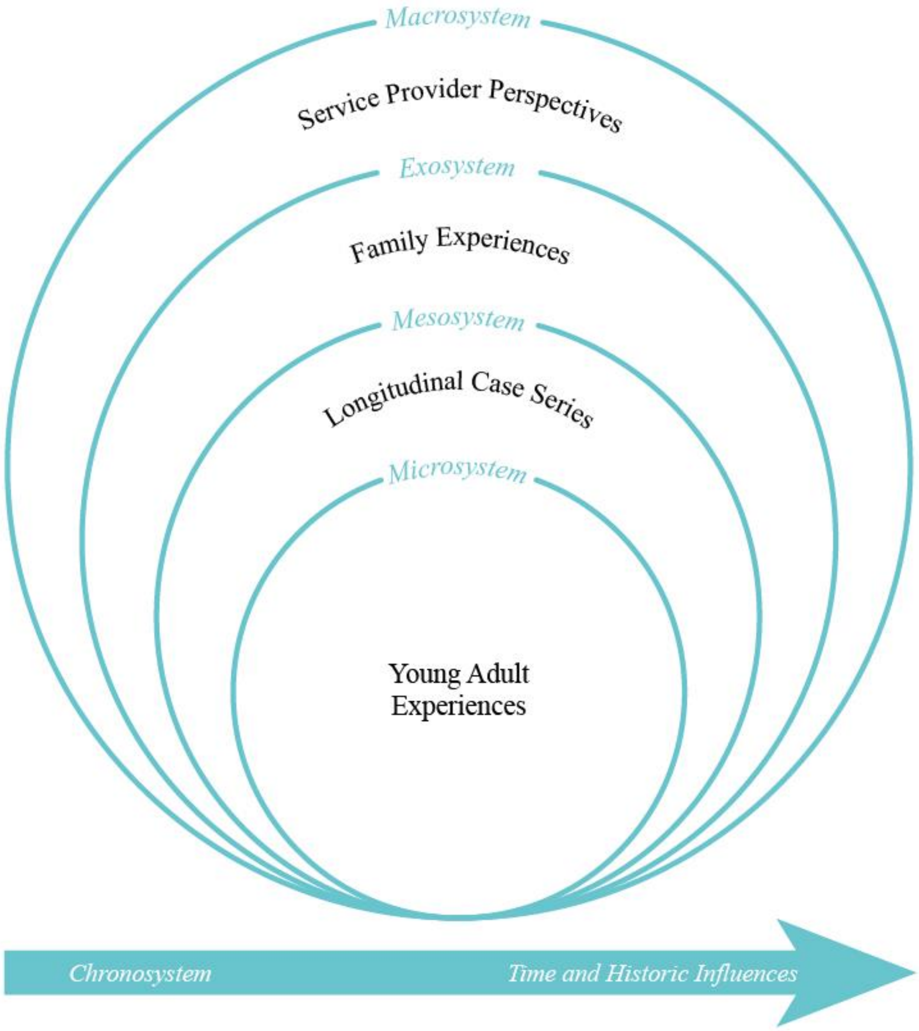


Figure 2.1. Bronfenbrenner’s Ecological Model (1994) adapted to the current program of research.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a lifelong developmental condition characterised by difficulties in social interaction, reciprocal communication, and stereotypical behaviour, interests or activities (APA, 2013). Difficulties in verbal and non-verbal communication include difficulty understanding body language, missing conversational cues, and interpreting information literally. As such, these individuals may not understand sarcasm, metaphors or words with double meanings, make inappropriate comments, and appear to be intentional in their inappropriate social behaviour (Attwood, 2008). Challenges in social interaction include avoiding eye contact, a failure to use social niceties, and an inability to provide the right information at the right time. In addition, individuals on the autism spectrum have difficulty understanding their own feelings and the feelings of others. As such, they may appear to be cold, literal, and concrete towards others (Attwood, 2008).

Autism Spectrum Disorder Prevalence

As discussed in Chapter 1, over the last decade Australia has seen an increase in individuals diagnosed on the autism spectrum (ABS, 2006; ABS, 2016). The increase in autism prevalence in Australia of 1 in 52 adolescents aged 13 to 15 years is comparative with prevalence rates in the US and internationally (Autism Asperger’s Advocacy Australia, 2015; ABS, 2016; Elsabbagh et al., 2012). For example, the Centers for Disease Control and Prevention (2014) estimated that 1 in 68 children identified as being on the autism spectrum in 2014, a significant increase over the last decade. According to recent research, a similar trend can be seen internationally (Elsabbagh et al., 2012; Matson & Kozlowski, 2011). For instance, Brugha et al. (2011) estimate the prevalence of ASD diagnoses with 1 in 100 adults diagnosed with ASD in the UK.

Whilst it is unclear why the prevalence of autism in Australia is increasing, it is suggested that broadening of the DSM-5 (APA, 2013) clinical diagnostic criteria implemented in 2013 resulted in the diagnosis of more individuals on the autism spectrum, and may have had an impact on the prevalence in 2015, relative to 2012 (ABS, 2016). Elsewhere it is suggested that an increase in early diagnosis as well as an increased awareness of autism by parents and professionals may have contributed to higher prevalence rates reported in 2015 when compared to 2012 (Australian Institute of Health and Welfare, 2017; Matson & Kozlowski, 2011; Weintraub, 2011).

Moreover, whilst the prevalence of ASD diagnosis has increased, the number of individuals on the autism spectrum within average to high intellectual ability has also increased, most likely due to early parent report of ASD, improved ability to recognise and diagnose individuals on the autism spectrum when symptoms are less severe, that is without the effects of an ID, which may in part have contributed to an overall increase in prevalence (Adreon & Durocher, 2007; Blumberg et al., 2013; California Department of Developmental Services, 2007; Centers for Disease Control, 2014). In addition, an increasing number of adults over the age of 18 are being diagnosed with ASD, likely due to these individuals realising that they are different, or having experienced difficulty receiving an earlier diagnosis in childhood (ASPECT, 2013; Brugha et al., 2011).

In Australia, the implication of the increase in prevalence for the future is that there would be an increase in the number of young adults on the autism spectrum requiring adult support services to facilitate a transition to life after high school. As such, there is a growing need firstly, to understand what the individual needs are of young adults on the autism spectrum within average to above average intellectual ability, so as to provide effective service provision, and secondly, to explore factors that are potential barriers, or factors that may help to facilitate a relatively smooth transition to adulthood.

Impact of Autism Spectrum Disorder

Globally and within the Australian context, there has been extensive research conducted on ASD in children, early intervention programs, and implications for families of young children. However, there is relatively little research on outcomes in adulthood, specifically for individuals with average to above average intellectual ability (see for example Hendricks & Wehman, 2009; Howlin & Moss, 2012; Tobin, Drager, & Richardson, 2014). Developmental difficulties of young adults on the autism spectrum are unique to each individual with variable presentations in social functioning and communication abilities and widely divergent outcomes (Hendricks, 2010). Due to the variability in difficulties and challenges in functioning, ASD is conceptualised as existing along a continuum of severity from mild to severe. Some studies have estimated that approximately 50% of individuals on the autism spectrum have within or above average intellectual ability (Centers for Disease Control, 2014). Such adults are generally considered to be more able than individuals on the autism spectrum with co-occurring ID (Howlin & Moss, 2012). For instance, some individuals within the average to above average range may engage in intelligent conversation with good verbal skills, are unlikely to be aloof, and may demonstrate high cognitive ability in employment settings. For these individuals, social and communication support needs are often unnoticed as a minority can find work, live independently, and develop relationships with others, and thus appear to have a good outcome in adulthood (Howlin et al., 2004). However, the majority remain without appropriate support services, and effective interventions, are employed in low paying menial jobs with a dependency on their families, the state medical, and welfare system (Billstedt, Gillberg, & Gillberg, 2005; Howlin et al., 2004; Migliore, Timmons, Butterworth, & Lugas, 2012). It is this divergent makeup of both ability and challenges that presents some confusion for neurotypical peers, professionals, and service providers who interact with young adults on the autism spectrum. Given the variability in outcome, it is important to understand factors that might be associated with different outcomes for young adults on the autism spectrum, to facilitate targeted interventions in an attempt to improve outcomes in adulthood, and alleviate a dependency on the state medical, and welfare system.

Disability Systems

For young adults on the autism spectrum leaving high school support systems, access to the adult disability system requires learning about new support structures, each with unique rules, regulations, eligibility guidelines, and procedures. Such change can be challenging, as it is known that disruption to routine can cause anxiety for individuals on the autism spectrum (Hendricks, 2010). Indeed, as young adults on the autism spectrum move from the familiarity of a structured school system to unfamiliar adult support services they may also experience a loss of support entitlements as they fail to meet adult support eligibility criteria (Taylor & Mailick, 2014).

The Australian disability system is comprised of support and services from a variety of formal government, not-for-profit, and private services that are available to individuals with disability to provide assistance in meeting daily living requirements (Queensland Government, 2016). Specifically, for young adults with a disability exiting high school, support is provided under the *Support for School Leavers* program, a government initiative rolled over into the National Disability Insurance Scheme (NDIS: Disability Programs, 2017). Types of support available include financial support accessed through the Disability Support Pension, Disability Service Providers (DSP), and Disability Employment Services (DES). DSP consist of support workers and case managers who work with individuals with a disability to access accommodation, community activities, respite, supported employment, and develop advocacy and volunteering activities (Queensland Government, 2016). DES offer specialist assistance to job seekers with a disability who require support to find and maintain employment. Such services include assistance with résumé development, job applications, and developing interview skills. Taken together, DSP and DES providers are two broad categories of support for individuals with disability, funded by the Australian government (Queensland Government, 2016).

Within the Australian school system, when students with disability exit high school, they no longer have the support and intervention of special education policy and supports accessed at the school level (Disability Programs, 2017). The new process to determine eligibility for support in the adult disability system is as follows: First, as adolescents with disability exit high school as young adults, they require a new diagnosis of a disability as an adult, from a specialist medical practitioner, including undergoing a comprehensive needs assessment by disability support services. Often the process of receiving a diagnosis is time consuming and expensive and may be perceived as a potential limitation to accessing the adult disability support system. Second, supports are provided based on a waiting list and prioritisation process, also known as a register of needs (Disability Programs, 2017). The implication is that young adults on the autism spectrum exiting high school receive support as they become available, not necessarily upon immediately leaving school, referred to colloquially as a "*lottery system*" (Australian Government Productivity Commission, 2011, p. 6). The instability and budget constraint of this infrastructure means that families in immediate crisis are given priority, leaving other individuals with disability without support. Indeed, recent research has found that a lack of ASD support services and decreased participation in daily activities after high school can impact mental health and wellbeing and increase the risk of behavioural difficulties for adults on the autism spectrum (Smith, Greenberg, & Mailick, 2012; Taylor & Seltzer, 2011). In particular, it is during the transition to adulthood that young adults on the autism spectrum often experience co-occurring mental health difficulties such as depression and anxiety, as they face normative role transitions, disruption to routine, reduced formal support, and increased responsibility (Bellini, 2006; Taylor & Mailick, 2014). Thus, services, support, and interventions play a pivotal role during the transition process. However, according to a recent Australian government enquiry, the current Australian adult disability support system is under-funded, complex to navigate, inefficient, with long waiting lists, and a high staff turnover (Australian Government Productivity Commission, 2011). In response to the overwhelmed adult disability support system, during the time of the present program of research, government legislation was passed in 2013 and the NDIS is being implemented from 2016 to 2019 across Australia.

National Disability Insurance Scheme

The NDIS is based on a person-centred approach that gives individuals with disability a choice of service provider and the option to self-manage their funding (Reddihough, Meehan, Stott, & Delacy, 2016). Key goals of the NDIS are to improve levels of participation in society, greater access to competitive employment, a range of accommodation options to meet individual needs and circumstances, and a reduction in the financial gap between individuals with and without disabilities. Disability under the NDIS eligibility requirements is defined as a "*loss of an ability to perform an activity which results from impairment*" (Australian Department of Human Services, 2015, p.2). Within the NDIS, individuals are eligible for support if they have a permanent disability attributed to intellectual, cognitive, neurological, sensory, or a physical condition, and are under the age of 65 years (Australian Department of Human Services, 2015). Further, individuals are eligible for support only if daily functioning at home or community access requires assistive modifications, for example the use of a wheelchair, or the support of others such as a caregiver. More specifically, autism is listed as a condition likely to meet the NDIS disability access requirements, only if diagnosed as Level 2, that is, requiring substantial support, or Level 3, that is, requiring very substantial support as determined by the DSM-5 diagnostic criteria (Australian Department of Human Services, 2015; APA, 2013). Additionally, a differentiation is made between individuals on the autism spectrum, and individuals on the autism spectrum with a disability (Australian Institute of Health and Welfare, 2017). This distinction would suggest that it is likely that individuals on the autism spectrum with average to above average intellectual ability may find it difficult to have their needs recognised and access services within the NDIS. Collectively therefore, it is unclear where individuals on the autism spectrum without co-occurring ID are positioned to meet the NDIS eligibility requirements to access support. As can be seen from the categories of support within the NDIS, narrow eligibility criteria limit the possibility of accessing support for some young adults on the autism spectrum (Australian Advisory Board on ASD, 2011).

Of note, recent research in Western Australia where individualised disability funding packages have been implemented for the last 25 years found that individualised funding did not result in more choice and greater opportunities for individuals with disabilities (Laragy, Fisher, Purcal, & Jenkinson, 2015). Instead, individuals with disability would benefit from firstly, access to more information to better inform their choices of services available and service providers, secondly, friendly, accepting, and welcoming communities, and, thirdly, support and advice from professionals such as social workers. Notably, 13% of service users within the NDIS between 2014 and 2015 were individuals on the autism spectrum, with the majority seeking community support services in therapy, early childhood intervention, and behaviour intervention (Australian Institute of Health and Welfare, 2016). In sum, the NDIS presents a new system of disability support for young adults on the autism spectrum to adjust to, and as such may in itself present difficulties in navigating access to services during the transition period.

Transition

Historically, transition is defined within economic terms as the shift from school to employment and is considered a major milestone in adult outcomes (see for example Halpern, 1985). At present transition is conceptualised as a period that includes high school completion, post-secondary education, the initial years of employment, functional independence, integrating with the community, and overall good personal and social relationships (Hendricks & Wehman, 2009; Wehman, 2006). For young adults aged 18 to 25 years, transition indicates a change in role status from the primary role of an adolescent to assuming adult positions within the community (Arnett, 2014; Halpern, 1993). It is therefore necessary to consider some aspects of adolescence that overlap into young adulthood.

Many adolescents are subject to experiencing two transitions simultaneously, first, the developmental stage of adolescence, and second, the shift to life after high school (Arnett, 2001). Although most young adults reach physical maturity by the age of 18, many continue to experience the storm and stress of adolescence in risk taking behaviour such as increased alcohol consumption and dangerous driving (Arnett, 2014). Moreover, as adolescence is a period where physical, cognitive, and social changes are experienced concurrently, the drive for independence and increased social and peer interactions may bring about feelings of being overwhelmed, leading to heightened stress (Arnett, 2014). For young adults on the autism spectrum, the transition may be especially challenging due to the defining traits of an ASD diagnosis. Therefore, individuals on the autism spectrum may present additional unique qualities that require planning and intervention to support the transition to adulthood.

Research suggests that negative events surrounding transitions, such as perceptions of failure or success, and adapting to changes in daily contexts may lead to a heightened vulnerability that can adversely impact on the psychological wellbeing of all adolescents (Fombonne, 1995). As such, transitions have been identified as inherently stressful for adolescents in general (Dornbusch, 2000). However, individuals on the autism spectrum may experience challenges in communication, social skills difficulties, behavioural issues, sensory concerns, and narrow, restricted interests that need to be supported during the transition to adulthood. Moreover, anxiety and depression may be underlying health difficulties that impact young adults on the autism spectrum, particularly during the transition to adulthood as these individuals experience increased changes in routine, roles, and responsibilities (Wehman, Schall, Carr, et al., 2014).

For typically developing adolescents, successful transitions are traditionally marked by good outcomes in post-secondary education completion, competitive paid employment that leads to financial security, independence in daily living skills such as mobility, a social network to facilitate leisure and recreational activities, and a sense of accomplishment as markers of having a good QOL (Hendricks & Wehman, 2009; Lawer, Brusilovskiy, Salzer, & Mandell, 2009; Taylor & Mailick, 2014; Wehman, 2006). Transitions to these adult roles require increased responsibility, adapting to different situations on a daily basis, meeting and interacting with new people. Such role transitions can be daunting for individuals on the autism spectrum in coping with unexpected changes of routine in physical, social, and sensory environments.

Across the literature, research on outcomes in individuals on the autism spectrum has been associated with successful or unsuccessful transition (Henninger, 2013). For instance, Howlin et al. (2004) operationalised good outcome categories associated with successful transition based on independent living, friendship, and occupation. Based on the outcome categories in the Howlin et al. (2004) study, several studies found that poor outcomes in work, friendships, and independent living were associated with unsuccessful transition and poor QOL (see for example Billstedt et al., 2005; Eaves & Ho, 2008). However, in a seminal study, Halpern (1993) highlighted the importance of achieving both individual needs and personal goals as well as meeting societal expectations, in facilitating a good person-environment fit. More recently, research with adults on the autism spectrum found that whilst the majority of participants were dependent on caregivers, which would suggest poor outcomes in independent living, their perceptions of transitions to education, occupation, and QOL were positive (Billstedt et al., 2011). Therefore, it is likely that the concept of a successful or unsuccessful transition differs across individuals and not all benchmarks may be applicable for all individuals. As such, QOL may offer one way of exploring successful and unsuccessful transition more broadly. Thus, it is important to also consider individual subjective perspectives when examining transitions and quality of life. Therefore, a case series approach in this thesis allowed for a closer examination of individual perspectives and how these perspectives are linked to QOL. In doing so, exploring individual experiences may allow for both positive and negative outcomes to be addressed based on an individual's perception of personal needs and individual goals within a person-environment fit.

Social Interaction

Research indicates that behavioural characteristics of ASD continue into late adolescence and early adulthood (Schall & McDonough, 2010). It is suggested that with age, some individuals are able to understand their differences more comprehensively and learn to compensate for and manage their ASD more effectively (van Heijst & Geurts, 2015). The concept of social relationships however, is more complicated (Lasgaard, Nielsen, Eriksen, & Goossens, 2010). Building social relationships, friendship formation, and establishing intimate partners are key developmental life stages for young adults (Arnett, 2014). As such, for young adults on the autism spectrum, difficulties in social interaction abilities and communication have a critical impact in adolescence and continue into young adulthood as these individuals navigate normative challenges compounded together with peer interactions and friendship formation (Barnhill, 2007; McDonald & Machalicek, 2013). Thus, social interaction during the transition period to adulthood may be particularly difficult for young adults.

According to a recent review by Tobin et al. (2014) many young adults on the autism spectrum expressed a desire to have friendships and social relationships, but lacked the social skills to initiate and maintain friendships. Indeed, difficulty in social skills is a hallmark of ASD. For instance, individuals on the autism spectrum experience challenges in attending to relevant social cues, and may engage in socially and emotionally inappropriate behaviour when initiating interpersonal relationships. Such individuals may be prone to social anxiety due to struggles in communication, conversational perspective taking, sensory overload, and limited ability to socialise with others (Bejerot, Eriksson, & Mortberg, 2014). In addition, understanding social conventions and social norms vary in different social situations, and are often difficult to predict or to manage when they arise. Hewitt (2011) refers to such social subtleties as hidden, and appropriate responses are determined by and dependent on the immediate context and situation. Collectively therefore, negotiating social situations with appropriate nuances is critically important to building social relationships and friendship formation, but presents a serious challenge for individuals on the autism spectrum.

Previous studies indicate increased social participation and interaction with others may be a potential avenue for adults on the autism spectrum to build communication skills and improve social functioning (Schall & McDonough, 2010). However, social interaction difficulties as experienced by young adults on the autism spectrum combined with social demands of adolescence may lead to withdrawal and social isolation (Shochet et al., 2016). As such, these individuals often have limited opportunity for social interaction to practice and improve their social skills. For instance, Orsmond, Shattuck, Cooper, Sterzing, and Anderson (2013) found high levels of social isolation in young adults on the autism spectrum when compared to individuals with ID, with almost 50% of individuals on the autism spectrum having no regular contact with friends. Those who did have some contact with friends lived independently, however, no information on their level of satisfaction with their friendships were reported (Orsmond et al., 2013). There is some controversy though, as to whether lack of friendships in some individuals on the autism spectrum is due to a lack of social skills in friendship formation. It may be the case that they have no interest in the social world, which is associated with the core challenges of ASD in fixated interests, and as such, they may prefer to be alone (Bauminger & Kasari, 2000).

Müller, Schuler, and Yates (2008) interviewed adults on the autism spectrum to explore how they navigated their social world. The researchers found themes associated with social experiences included isolation, longing for intimacy and social connectedness, interest in contributing to the community, and development of greater self and social awareness. Müller et al. (2008) found that most participants reported volunteering for non-profit organisations, and working with children in an effort to contribute meaningfully to the community, and attempted to compensate for their difficulties and challenges by joining autism support groups, and social skills groups. However, the majority of participants in their study belonged to autism support groups and received intervention therapy for social cognition difficulties. Thus, it may be that participants demonstrated an increased level of social awareness and introspection in managing their social challenges and may not be a true representation of how other individuals on the autism spectrum navigate their social worlds (Müller et al., 2008).

In sum, navigating individual social situations with appropriate interactions presents a challenge for young adults on the autism spectrum. Consequently, these individuals often enter adulthood with limited experience in social interactions, challenges with social skills, and a lack of social support due to continuous difficulties in the social realm. Indeed, social support is an important coping resource that functions as a buffer against life-stresses, enhances self-esteem, and a sense of belonging (Helgeson, 2003).

Social Support

According to Helgeson (2003) social support is conceptualised as the different ways that individuals behave in the social environment and typically includes two measures of support. First, structural measures of social relationships include the number of individuals and type of relationships within a social network, and, second, functional measures include the type of resources provided within a social network, for example emotional support from family and friends. Furthermore, according to Helgeson (2003) when an individual experiences increased stress, social support serves as a buffer which suggests that being involved in social networks and having people to talk to can contribute to a better QOL. Therefore, investigating social support is important given the difficulty associated in navigating social situations during the transition to adulthood.

Researchers investigating the social network characteristics of older adults on the autism spectrum and adults with ID found that although adults on the autism spectrum had smaller family and friendship networks when compared with adults with ID, they wanted more meaningful relationships with both friends and family members and hoped to expand their network of friends to include partners (van Asselt-Goverts, Embregts, Hendriks, Wegman, & Teunisse, 2015). These findings highlight the important role of friends, family members, and a partner in social support networks of some adults on the autism spectrum. Of note, van Asselt-Goverts et al. (2015) acknowledge that participants in their study were living independently in the community and as such, younger adults living with parents may have a different perspective on social support networks.

Perceived social support has been shown to be a stress-buffer and is closely linked to physical and mental wellbeing, social connectedness, and loneliness for neurotypical individuals (Alvarez-Fernandez et al., 2017; Uchino, Bowen, Carlisle, & Birmingham, 2012). Loneliness is related to inadequacies in social relationships, is associated with mental health problems and anxiety, and is prevalent during the developmental period of adolescence (Lasgaard et al., 2010). In a study examining loneliness and perceived social support in adolescent males on the autism spectrum, perceived social support from peers, parents, and close friends emerged as an important protective factor against loneliness (Lasgaard et al., 2010). Furthermore, those participants with two or more siblings reported feeling less lonely than those without siblings. Interestingly, according to Lasgaard et al. (2010) whilst some participants acknowledged difficulty making friends, they were not lonely and preferred to choose whether to have friends or not. Nevertheless, all participants in the study by Lasgaard et al. (2010) were recruited from special education schools, and experienced severe behaviour problems and learning difficulties, which may have influenced the estimated prevalence of loneliness in participants in this study.

Similarly, qualitative interviews with academically successful adults on the autism spectrum identified friends, parents, and family members as important people who provided support in their daily lives (Robledo & Donnellan, 2016). Participants identified common interest and values, trust, respect, and level of comfort within the relationship as factors supporting their success in adulthood. Whilst all participants in the study by Robledo and Donnellan (2016) identified mothers as being a significant support figure in their lives, the issue of being "*over-supported*" was seen as an obstacle to achieving independence in adulthood (Robledo & Donnellan, 2016, p. 25). Indeed, mothers in this study acknowledged the underlying tension in being a supportive parent and had difficulty recognising when was the right time to "*let go*", and admitted that this tension was an ongoing challenge for them as parents (Robledo & Donnellan, 2016, p. 26). Thus, whilst mothers in this study played a major support role in the lives of their adult children, there was a discrepancy as to whether such intense supervision was beneficial in facilitating independence in adulthood (Manos, 2009). Nevertheless, only some participants had a formal diagnosis of ASD with most being self-diagnosed. Taken together, findings from both Lasgaard et al. (2010) and Robledo and Donnellan (2016) provide important information on the important role of social support role of families and friends both as a protective factor to loneliness, as well as a facilitator to independence and success in adulthood.

Social Outcomes in Adulthood

Young adults on the autism spectrum display varying outcomes in adulthood that may in part be attributed to difficulty in social interaction and communication, restrictive and repetitive behaviour, and mental health issues (Howlin et al., 2004; Marriage et al., 2009). There is some evidence that adults with higher intellectual ability have better social outcomes although this is not consistently reported (Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989). For instance, in a longitudinal study Mordre et al. (2012) found that adults on the autism spectrum with above average intellectual ability experienced poorer relationships, low levels of independence in living, and limited employment when compared to other individuals on the autism spectrum. According to the researchers, psychosocial difficulties and poor adaptive behaviour associated with ASD were predictive of poorer outcomes in adulthood with the majority of participants in their study dependent on the state welfare system. Thus, these findings by Mordre et al. (2012) suggest that whilst individuals on the autism spectrum may have average to high intellectual ability, social interaction and communication difficulties present challenges in their adult lives.

In a similar context, a study by Howlin et al. (2004) with adults on the autism spectrum of average and high intellectual ability aged 21 to 48 years, found high rates of dependency on families, welfare services, and supported employment for all adults in their study. Howlin et al. suggest that this dependency may be related to challenges of an ASD in fixated interests and stereotypical behaviour rather than intelligence. Moreover, those male participants with poor employment outcomes demonstrated socially inappropriate behaviour with females in the workplace (Howlin et al., 2004). A possible explanation therefore, is that despite average to high intellectual ability, the fundamental challenge in social etiquette associated with ASD continues into adulthood and in interactions with peers and workplace colleagues. Notably, Howlin et al. suggest that the ability to function effectively in adulthood may be dependent on support from families and support services, although support was not explored further in their study.

Similarly, another study with adults on the autism spectrum with high intellectual ability found that more than three quarters of participants lived with parents, only half were in competitive employment, and half were in a day activity program (Renty & Roeyers, 2006). Their findings that intelligence and ASD traits did not impact on the QOL of young adults, is in contrast to findings by Howlin et al. (2004). Rather, in the study by Renty and Roeyers (2006), perceived social support from family and social networks was closely linked to personal wellbeing and improved QOL. This result emphasises the importance of an available supportive social network for adults on the autism spectrum to improve overall wellbeing. However, participants in the study by Renty and Roeyers (2006) demonstrated good communication and social skills, and thus, overall, initially may have had a good QOL. As such, it is unclear whether participants overall initial good QOL impacted perceptions of better social support in the study, or indeed, if high levels of support improved their QOL.

One Australian longitudinal study with adults on the autism spectrum found that post-school outcomes in independent living skills, community integration, and employment were poor (Gray et al., 2014). Gray et al. (2014) found that more than half of the participants, all with co-occurring ID, were dependent on parents as caregivers, had limited social inclusion, with only a small percentage in paid employment. However, little information was provided as to the potential factors associated with improved independence and better social inclusion in adulthood. Indeed, Gray et al. (2014) acknowledge the scarcity of literature on predictors of adult outcomes in populations on the autism spectrum in Australia and suggest further research is needed to identify individual and environmental factors that promote independence and social inclusion in adulthood. Thus, there is limited knowledge of factors associated with outcomes in the population of young adults on the autism spectrum without co-occurring ID in Australia.

Given the differences in study findings, it is difficult to draw any conclusions. It is plausible that variation across studies may be attributed in part to a variety of measures used, differences in characteristics of study populations, and potentially, implementation of different ASD classification systems. Therefore, exploring individual experiences may provide further insight into transition outcomes in adulthood in such areas as identified in the literature of post-secondary education, employment, social interaction, independent living, and QOL.

Quality of Life

QOL is defined as an individual’s position in relationship to their culture, value system, goals, standards, expectations, and concerns (WHOQOL Group, 1998). QOL incorporates eight core domains conceptualised as factors that reflect an individual’s personal wellbeing (Schalock, 2004). These eight domains are, emotional wellbeing, interpersonal relations, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion, and human rights. Emotional wellbeing incorporates an individual’s subjective perception of self-esteem, identity, and overall satisfaction. Interpersonal relations include interactions within social networks, relationships with family, friends and peers, and emotional and physical support. Material wellbeing relates to employment, work status, and work environment. Personal development is linked to education with regards to success and achievement. Physical wellbeing incorporates activities of daily living, mobility, leisure, and recreation. Self-determination focuses on autonomy, choice, goals, and personal values. Social inclusion considers support networks, community integration and participation. Human rights include respect, dignity, and equality (Schalock & Verdugo, 2002).

QOL is therefore a multidimensional construct comprised of both subjective and objective components and is influenced by personal and environmental factors such as relationships, employment, housing, education, and health. Research examining objective indicators of QOL such as independence, income, employment, and social relationship in adults on the autism spectrum found overall low QOL when compared with neurotypical peers (Eaves & Ho, 2008; Howlin, 2000; Howlin et al., 2004). Factors associated with positive outcomes in adulthood for adults on the autism spectrum appear to include higher intellectual ability, a supportive social network, and access to support services (Howlin, 2000; Howlin et al., 2004; Howlin & Yates, 1999).

Indeed, individuals live in many different systems that influence their values, attitudes, beliefs, and behaviour. As such, QOL is intricately woven into the daily life contexts in which people live and interact. Due to the multidimensional and complex nature of QOL, the use of methodological pluralism that includes the use of subjective and objective measures is suggested. Further, Schalock (2004) suggests an ecological approach to understand the different systems that influence individual values, attitudes, beliefs, and behaviour.

According to Ecological Systems Theory (EST: Bronfenbrenner, 1994) at the microsystem level the subjective nature of QOL represents individual personal appraisal of perceived wellbeing, social support, social integration, trust, independence, self-confidence, aspirations and expectations related to family, jobs, and life in general (Schalock, 2004). At the mesosystem level the objective nature of QOL represents structured support, specialised training, and opportunities to meet the specific needs of young adults on the autism spectrum. Such opportunities include community integration, social inclusion, and self-determination by encouraging choice. At the macrosystem level, disability policies and practices serve as a conceptual basis to facilitate support and inclusion of young adults on the autism spectrum within the broader societal and environmental context (Schalock, 2004). As such, the overarching patterns of culture, socio-political trends, economic systems, and society related factors that directly influence an individual's values are considered within the macrosystem. Therefore, within a holistic context, it can be seen that young adults on the autism spectrum are vulnerable to all aspects of systemic infrastructure through family connectedness, social and community access, post-secondary education, and disability policy implementation.

The concept of QOL has been used to describe outcomes in areas such as education and social services for adults with ID and developmental disabilities (Schalock, 2004). It is recognised that an individual is more likely to experience a high QOL if important needs in major life settings of education, work, home, and community are fulfilled (Gerhardt & Lainer, 2011; Roux et al., 2013). A search of the literature on Australian research examining QOL in young Australian adults on the autism spectrum revealed limited research with studies focusing on children on the autism spectrum, families, or adults with ID. The following findings are briefly presented to provide a context for QOL and ASD in Australia. First, with respect to studies with children for example, one Australian study compared the prevalence of parent reported ASD and QOL in children aged two, and children aged seven (Randall et al., 2016). Both groups of children in their study experienced a poor QOL, and difficult behaviour when compared to neurotypical peers. Second, with respect to families, two Australian studies explored the QOL of families of children on the autism spectrum, and other disabilities (McStay, Trembath, & Dissanayake, 2014; Tait & Hussain, 2017). For example, McStay et al. (2014) explored predictors of parental stress and family QOL in both mothers and fathers of children on the autism spectrum. Findings showed that mothers of children on the autism spectrum experienced significantly higher levels of stress, and lower family QOL when compared to fathers.

Third, with respect to studies with adults for example, one Australian study examined the QOL of 34 adults with ID in a community based support service (Rapley & Hopgood, 1997). Findings indicated that participants demonstrated little autonomy, limited independent living, and poor community participation. However, this study was limited to adults with ID. A second Australian study with adults compared subjective QOL in 80 young adults with ID, and 120 young adults without ID (Bramston, Chipuer, & Pretty, 2005). Young adults in their study rated higher satisfaction with health, and lower satisfaction with intimacy, and community participation when compared to young adults without ID. Additionally, social support emerged as the strongest predictor of material wellbeing and overall life satisfaction across both groups of participants. Indeed, Bramston et al. (2005) acknowledge the

QOL concept as a unifying framework when comparing concepts of material wellbeing, health, productivity, intimacy, safety, community, and emotional wellbeing in both adults with and without ID. Although both Australian studies by Rapley and Hopgood (1997) and Bramston et al. (2005) explored QOL in adults relevant to the present program of research in this thesis, their studies are limited to adults with ID. As is evident, due to limited research specifically with young adults on the autism spectrum in Australia, little is known about the factors that contribute to QOL for this population specifically.

QOL in adults on the autism spectrum has been reported in the international literature with outcomes varying from good to poor. In Sweden, Billstedt, Gillberg, and Gillberg (2011) conducted a prospective long-term follow-up study of 108 adults on the autism spectrum from childhood into early adulthood implementing a newly developed autism friendly environment scale. The majority of adults in their study were dependent on parents and caregivers for support in education, accommodation, and occupational activities. Good QOL was associated with regular recreational activity and community involvement, with only 33% of participants indicating regular recreational involvement. Further, the majority of adults in their study lacked a daytime occupation, with only seven adults in supported employment. In addition, only thirteen individuals reported having friends with the majority indicating limited understanding of friendship formation. Whilst the researchers identify a need for further investigation into improvements in recreational activities, they also highlight the need for a detailed QOL assessment tool for individuals on the autism spectrum.

In a related context, research with 42 older Swedish adults on the autism spectrum with high intellectual ability, found that only one adult was employed, none were married, more than half of the adults received the disability pension, and there was a need for extensive family support amongst most (Engström, Ekström, & Emilsson, 2003). Further, although nine adults in the sample lived independently they required high levels of support. These results indicate that although these individuals were of high intellectual ability, they depended on regular support from family and friends to meet daily living needs. Indeed, Engström et al. (2003) suggest that further research is conducted to explore psychosocial conditions and QOL, so that targeted interventions can be developed to meet the needs of adults on the autism spectrum with high intellectual ability. Similarly, in Canada, Jennes-Coussens, Magill-Evans, and Koning (2006) compared QOL of 12 adult males with Asperger Syndrome to that of 13 neurotypical adult males. Results indicate that adults with Asperger Syndrome reported a lower social and physical QOL when compared to neurotypical peers. Whilst education, living arrangements, and the number of friends were similar in both groups, only half of the adults with Asperger Syndrome were employed. Additionally, employment outcomes for adults with Asperger syndrome were higher in unskilled job categories with less pay when compared their neurotypical peers. A limitation of this study is the gender specific male sample. Importantly, the researchers suggest that future research also includes parents of adults with Asperger Syndrome to provide a holistic understanding of factors associated with QOL.

In Japan, Kamio, Inada, and Koyama (2012) investigated QOL and psychosocial outcomes in a survey study with 154 adults on the autism spectrum with high intellectual ability. Of the participants in their study, almost all lived with parents, and three quarters were unemployed. The researchers found that support from mothers was associated with improved psychosocial QOL for adults in their study, although Japanese child-rearing practices predominantly by mothers is highlighted as a possible cultural bias associated with the importance of mothers’ support (Kamio et al., 2012).

In the US, Pfeiffer et al. (2017) conducted a qualitative study with five adults on the autism spectrum to explore their perceptions of interventions and impact on QOL. Two themes emerged from their interview study. With regards to the first theme of misconceptions, adults in their study described their emotions, need for social interactions, and relationships as being misunderstood by neurotypical peers, and negatively impacting their QOL. With respect to the second theme of specific interventions, adults perceived special education supports, psychological counselling, and support groups as helpful interventions to improve social skills (Pfeiffer et al., 2017). Those individuals who received a later diagnosis as adults reported a sense of relief in knowing that they were not alone, but shared similar challenges and difficulties with other adults on the autism spectrum. Notably, all adults in this study belonged to ASD support groups, and as such may show an affinity to community based interventions, which may differ from other adults on the autism spectrum.

From the international research then, it can be seen that QOL outcomes appear poorer, but vary in adults on the autism spectrum. Given the limited research on QOL and outcomes with Australian adults on the autism spectrum, it is important to explore what factors might be associated with good QOL and poor QOL outcomes during transition in the Australian population of young adults on the autism spectrum. Two normative role transitions to adulthood associated with QOL are the transition to post-secondary education and employment (Shattuck et al., 2012).

Transition to Post-Secondary Education

Successfully transitioning from high school to post-secondary education can improve future employment options, increase financial independence, and improve QOL in adulthood (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012; Hendrickson et al., 2013; Lee & Carter, 2012). According to recent data, 35% of young adults on the autism spectrum in Australia graduated from university when compared to 50 to 67% of neurotypical peers (Universities Australia, 2015). In addition, the ABS (2012) reported that 81% of adults on the autism spectrum in Australia do not have a post-secondary qualification. Therefore, investigating factors that can contribute to positive post-secondary education outcomes for young adults on the autism spectrum in Australia has the potential to contribute to improving focused transition planning at the school and post-school level, and further promote post-secondary education outcomes.

According to recent research, it is suggested that due to awareness of early intervention programmes, disability legislation, support in high schools, and cognitive ability, an increasing number of young adults on the autism spectrum are enrolling in post-secondary education (Adreon & Durocher, 2007; Barnhill, 2016; Pillay & Bhat, 2012; VanBergeijk et al., 2008). However, post-secondary education extends beyond academic engagement and involves a change in daily routine, socialising with peers, and opportunities for membership of social clubs (Attwood, 2008). For young adults on the autism spectrum, it is likely that the combination of ASD associated challenges and change in routine and structure, adjusting to a new environment, and meeting new peers during the first six months of post-secondary education, may elevate anxiety and depression thus impacting their ability to reach their academic potential (VanBergeik et al., 2008). Therefore, whilst young adults on the autism spectrum may be intellectually capable of engaging in post-secondary education, difficulty in interpersonal and social communication, lack of confidence, and social skills difficulties may compromise their ability to integrate into a new setting impacting post-secondary education completion (Mitchell & Beresford, 2014; Müller et al., 2008).

In Australia, post-secondary education is comprised of Technical and Further Education (TAFE) colleges and universities where students with a disability have access to learning support systems through student support services (Adreon & Durocher, 2007). However, access to this support typically requires disability disclosure, and advocating for support provision, which involves interaction skills that pose a communication difficulty for students on the autism spectrum (VanBergeijk et al., 2008). As such, it is suggested that students register with disability support services at tertiary institutions to be eligible for support provisions (VanBergeijk et al., 2008). However, in disclosing their ASD, young adults face the risk of being stigmatised as incapable (Davidson & Henderson, 2010). Moreover, it may be the case that whilst academic support is available at tertiary institutions, social support requirements and communication difficulties of students on the autism spectrum may appear subtle, and therefore are overlooked. Indeed, it might be confusing for tertiary support services to comprehend that students who are academically capable might need support with social interactions and communication (Hewitt, 2011). It is therefore necessary that opportunities are provided at high school for students to practice independent problem-solving and self-advocacy skills as part of the transition planning process so as to build their confidence in post-secondary education.

On a global level, several studies have documented poor post-secondary outcomes for young adults on the autism spectrum (see for example Adreon & Durocher, 2007; Chiang et al., 2012; Wei, Wagner, Hudson, Yu, & Shattuck, 2015). For instance, research conducted in the US by Shattuck et al. (2012) found that young adults on the autism spectrum when compared to young adults with a disability had the lowest rates in post-secondary education for the first two years after high school.

These findings suggest that targeted transition planning for individuals on the autism spectrum is needed to address barriers to participation in post-secondary education specific for this group. Similarly, in a national longitudinal study conducted in the US by Wei et al. (2015), young adults on the autism spectrum had the lowest rates of enrolment at college with more than 50% neither employed nor in post-secondary education. Further, another national longitudinal study conducted in the US by Chiang et al. (2012) found parental expectation of post-secondary education participation, academic achievement, school transition-goals specific to post-secondary education, and student participation in transition planning were significant predictors of participation in post-secondary education. Therefore, targeted transition planning at the school level as identified by Chiang et al. (2012) is crucial to facilitating a seamless shift to post-secondary education. As such, for young adults on the autism spectrum, it seems necessary to include organisational, social, and independent living skills as part of the transition planning process at high school as a support structure during the transition to post-secondary education (Adreon & Durocher, 2007). Within the Australian context however, there is limited research exploring the transition planning process specifically for individuals on the autism spectrum (Beamish et al., 2012).

In order to manage with change at post-secondary institutions, research suggests that with continued planning and support at post-secondary institutions in both the academic and social realm, students on the autism spectrum can be successful in post-secondary education (Adreon & Durocher, 2007; VanBergeik et al., 2008). For instance, a recent survey conducted by Barnhill (2016) across 30 post-secondary institutions in the US found that the most common support accessed by students on the autism spectrum were links to a support advisor, extra time for exams, alternate test site, and extra tutoring time. In addition, a few institutions provided a summer transition program specifically for students on the autism spectrum and activities included social skills instruction, and life skills activities such as laundry and time management (Barnhill, 2016). The researchers noted that regular communication with parents in their study provided valuable insights on their child's post-secondary education needs. Unfortunately, such support programs for individuals on the autism spectrum were not consistently advertised on university websites in this study (Barnhill, 2016).

Research on the transition to post-secondary education for young adults on the autism spectrum in Australia is sparse. One Australian focus group study with young adults on the autism spectrum by Cai and Richdale (2016) found that whilst students reported receiving effective academic support with assignment extension dates and exam arrangements, they received limited social support. Further, these students reported that support staff often had limited knowledge of ASD, displayed negative attitudes towards them, and lacked support resources, which would suggest the need for specialist ASD support staff. A key consideration that emerged within the study by Cai and Richdale was the necessity for ASD disclosure in order to access support in post-secondary education. However, many students in their study were reluctant to disclose their ASD for several reasons including being discriminated against and possibly perceived as being different. Further, Cai and Richdale note the potential mental health consequences of stress, anxiety and depression, or in a worse case scenario, dropping out of university due to an inability to cope with a combination of academic and social demands. Interestingly, the researchers note that many parents reported attempting to communicate with university staff regarding the support needs of their child, but were blocked by privacy laws in their conversations. Thus, Cai and

Richdale suggest that more research is needed in Australia to understand the best ways for providing academic and social support to young adults on the autism spectrum in post-secondary education.

Similarly, in Belgium, interviews with post-secondary students on the autism spectrum found students experienced challenges in coping with new routines and structures, timeframes and time management, difficulty fitting in with new friendships, and sensory overload to the sound of typing on computers and flickering lights (Van Hees, Moyson, & Roeyers, 2015). According to Van Hees et al. (2015) students were doubtful about disclosing their diagnosis for fear of stigmatisation and prejudiced behaviour, a lack of privacy, and wanting to make a fresh start, consequently, they experienced stress, anxiety, and depression and were often fatigued in coping with challenges. However, the researchers note some benefits in ASD disclosure of increased understanding from academic staff in making assignment accommodations. Nevertheless, all participants in this study were active participants in their transition planning, and had an in-depth understanding of their ASD, which may have resulted in selection bias in their willingness to participate in this study (Van Hees et al., 2015).

Collectively, within the research on post-secondary outcomes, findings highlight the importance of ASD disclosure, the continued support at post-secondary institutions in the academic and social realm, underpinned by trained support staff as crucial for success in post-secondary education. Notably, the role of the family and the student in the transition planning process is highlighted to facilitate a seamless shift into post-secondary education. Within the Australian context however, research in the area of transition and post-secondary education is sparse (Cai & Richdale, 2016). Indeed, according to research, further planning from high school to employment should also be considered as many young adults on the autism spectrum are at risk of unemployment or underemployment (Higgins, Koch, Boughfman, and Vierstra, 2008; VanBergeijk et al., 2008; Zager & Alpern, 2010). Given the central role that employment plays as a pathway to success in adulthood, it is also necessary to consider factors associated with the successful transition to employment.

Transition to Employment

Participation in employment, job related status, and increased financial independence in adulthood is considered essential components to success in adulthood and QOL (Gerhardt & Lainer, 2011; Roux et al., 2013). Types of employment broadly identified in the literature include competitive paid employment that allows individuals on the autism spectrum to earn wages at the same rate as neurotypical peers (Lawer et al., 2009). Supported employment provides disability specific support so that individuals on the autism spectrum are able to access integrated employment and earn the same wages as neurotypical peers.

Being in competitive paid employment improves self-esteem, independence, provides an opportunity for socialisation, friendships, and being a productive member of the community, as well as contributing to financial wellbeing (Lee & Carter, 2012; Wehman, 2011). However, research indicates that young adults on the autism spectrum have a low rate of employment in the first two years post-school when compared to adolescents diagnosed with ID, learning disabilities, or specific language impairments (Hendricks, 2010; Shattuck et al., 2012; Taylor et al., 2012; Wehman, Schall, McDonough, Kregel, et al., 2014). In many instances, the type of work accessed is menial (e.g., washing dishes, shredding paper), at a lower pay, with fewer hours, leading to a dependency on family, the state medical, and welfare system with a poor QOL for these individuals (Migliore et al., 2012; Taylor et al., 2012).

Although young adults on the autism spectrum may be cognitively capable of meaningful employment, the debilitating impact of fixated routines, limited social-skills, and communication difficulties often act as barriers to gaining and maintaining successful competitive paid employment (Higgins et al., 2008; Schaller & Yang, 2005). Consequently, they are more likely to be unemployed, underemployed in jobs that are below their ability levels, or mal-employed, in jobs for which they are unsuited (Higgins et al., 2008; Hurlbutt & Chalmers, 2004; Müller, Schuler, Burton, & Yates, 2003; Romoser, 2000; Schaller & Yang, 2005; Taylor & Seltzer, 2011; Wilczynski, Trammell, & Clarke, 2013). More specifically, according to recent data, the unemployment rate for Australian adults on the autism spectrum is more than three times the rate for individuals with disability and almost six times the rate of neurotypical adults (ABS, 2016). Indeed, as discussed in Chapter 1, a recent review by Synergies Economic Consulting (2011) estimated the annual cost of ASD in Australia between $8.1 billion and $11.2 billion with the most significant impact in reduced income due to low employment rates.

Higgins et al. (2008) identify challenges in communication, social skills, and adaptive behaviour impacting transition to the workplace. In terms of communication, employment interviews present an initial barrier for adolescents on the autism spectrum. Interactional difficulties mean that these individuals are met with challenges of understanding social norms, facial expressions, body language, and tone of voice. For example, good listening skills, demonstrating empathy for others, and responding appropriately to body language are some social skills necessary for effective teamwork. In addition, the ability to follow employer instructions, to multitask, respond to feedback, and work in environments with loud noise, fluorescent lights, and strong smells may pose challenges for adults on the autism spectrum (Higgins et al., 2008; Hurlbutt & Chalmers, 2004). As a result of these challenges, individuals on the autism spectrum demonstrate frequent job switching, potentially impacting the opportunity for career development, and as such, are susceptible to stress, depression, and financial insecurity (Hendricks, 2010; Müller et al., 2003).

There is however evidence in the international literature to support the benefits of employing individuals on the autism spectrum. First, employers value their honesty, trustworthiness, loyalty, and typically low levels of absenteeism (Hagner & Cooney, 2005; Hendricks, 2010; Stankova & Trajkovski, 2010). In addition, their attention to detail, enjoyment of working in isolation, and tolerance for repetitive activities can be effectively matched to suitable employment opportunities (Hagner & Cooney, 2005; Hendricks, 2010). However, in the workplace, many adults on the autism spectrum present a contradictory employment profile. On the one hand, they are viewed as excellent employees with commitment to tasks and attention to detail. On the other hand, they are viewed as difficult employees when considering their social and behaviour challenges (Hagner & Cooney, 2005; Johnson & Joshi, 2014; Müller et al., 2003). In addition, ritualistic patterns of behaviour and fixated special interests typically associated with ASD stigmatise these individuals as *odd* rendering them vulnerable to being teased and bullied in the workplace (Hendricks, 2010). As a result, individuals on the autism spectrum may appear socially inept and are at an increased risk of job loss due to general miscommunication.

In an emerging body of Australian research on individuals on the autism spectrum, a survey study conducted by ASPECT (2013) found that only 54% of adults with high intellectual ability were in competitive employment, compared to the Australian national employment rate of 95%. Of the 54%, 33% of adults in their study were employed on a casual basis, with a third in voluntary or unpaid work. According to ASPECT (2013), 31% of adults were supported by disability employment services to find employment, and 22% received informal support from family and friends. Further, the majority of adults in this study by ASPECT (2013) reported receiving no support in the workplace yet 68% indicated a need for support in social skills, communication, and access to workplace counselling. The researchers note that, of those young adults who were employed, negative experiences included dissatisfaction with job roles, difficulty with work relationships, and health and wellbeing concerns associated with ASD that impacted the ability to work. However, this Australian survey study included adults within the broader age group of 18 to 70 years old, many having surpassed young adulthood, and some of who were self-diagnosed as being on the autism spectrum (ASPECT, 2013). As such, these findings limit the generalisability to the young adult population aged 18 to 25 in the present program of research, currently experiencing the transition to adulthood. Further, this study by ASPECT (2013) did not identify factors that led to improved outcomes for this group.

On a global level, several studies have documented outcomes in employment for adults on the autism spectrum with different levels of functioning and across broad age groups (Pillay & Brownlow, 2017). In a study conducted in the US, Müller et al. (2003) interviewed 18 adults with Asperger Syndrome aged 18 to 62 years, to explore their experiences within the workplace. Most adults spoke of their employment in negative terms, with difficulty not being able to fit into the workplace, misunderstanding employer requirements, and feeling socially isolated. Many reported long periods of unemployment due to repeatedly being fired from jobs, making it difficult to find further employment. Müller et al. (2003) found positive experiences included having a job matched with their individual skill set, clear instructions from the employer, and a job routine that remained the same from day-to-day. Adults in the study described a good job match as one that tapped into the individual’s special interest, required minimal social interaction, had clearly defined structure and routines, minimal sensory stimulation, and allowed for flexible work schedules. Of note, many adults in the study by Müller et al. (2003) acknowledged their ASD strengths, and suggested that job matching would contribute to improved independence, competence, and success. A limitation of the study by Müller et al. (2003) however, is the broad age group of adults of 18 to 62 years, with most having received a diagnosis after the age of 21, and as such, not have had access to early support and intervention. Thus, these findings must be interpreted with caution with respect to the younger adult population.

A study by Taylor and Seltzer (2011) found that outcomes in daytime activities and competitive employment were three times lower for young adults on the autism spectrum when compared with young adults on the autism spectrum and co-occurring ID (Taylor & Seltzer, 2011). Moreover, in their study, only 18% of young adults on the autism spectrum accessed supported employment when compared to 86% of young adults with co-occurring ID. Further, the researchers found that young adults with an ASD only diagnosis accessed more competitive paid employment, and those with a co-occurring ID accessed increased competitive paid employment as well as increased sheltered community employment. The low number of adults on the autism spectrum without ID that gained employment in this study suggests a lack of ASD specific services. As such, these findings indicate better access and community support for individuals with co-occurring ID and would suggest that more autism focused employment services are needed to facilitate access for individuals on the autism spectrum to achieve sustainable employment during the transition to adulthood (Taylor & Seltzer, 2011). However, young adults in their study were skewed towards a higher socio-economic demographic, and as such, findings cannot be generalised to the general population of individuals on the autism spectrum.

Research has identified that ASD symptoms deteriorate post-school through a lack of continued specialised intervention in the adult vocational system (Lee & Carter, 2012; Taylor & Seltzer, 2011). The demand to facilitate supported adolescent transition successfully into employment is highlighted by outcomes in a historical review indicating only a small percentage of adults on the autism spectrum access competitive paid employment in integrated settings over time (Henninger & Taylor, 2013). Some studies recognise that with support, training, and education, individuals on the autism spectrum can work in competitive employment (Hendricks & Wehman, 2009; Hurlbutt & Chalmers, 2004). For instance, studies examining successful transitions into post-school employment have identified the benefits of supported workplace intervention in facilitating individuals on the autism spectrum in a regular workplace environment implementing job-placement services, mentoring programs, job coaches, workplace mentors, trained staff, behaviour interventions, and social skills programs (Mawhood & Howlin, 1999; Migliore et al., 2012; Nuehring & Sitlington, 2003; Pillay & Brownlow, 2017; Taylor et al., 2012; Wehman, Schall, McDonough, Kregel, et al., 2014; Wehman, Schall, McDonough, Molinelli, et al., 2013). Findings indicate that with supported intervention, adults accessed increased competitive paid employment with increased pay and increased hours per week leading to a better QOL. However, these findings are limited to outcomes in employment. Given the heterogeneity in individual, social, communication, and behavioural difficulties in adolescents on the autism spectrum, a variety of vocational interventions are necessary to address individual needs (Hendricks, 2010; Pillay & Brownlow, 2017). Individuals on the autism spectrum are therefore considered high needs by employers, requiring more expensive support services to access employment (Lawer et al., 2009). Indeed, it is recognised that liaising with employers in planning and matching suitable job types is the most expensive cost factor associated with planning transition to employment (Mawhood & Howlin, 1999). It can be seen then, that due to their unique characteristics combined with social and communication challenges in the workplace, unemployment and underemployment are significant concerns for adults on the autism spectrum.

Similarly, a recent review by Jacob, Scott, Falkmer, and Falkmer (2015) provided insight into the economic benefits of employment for individuals on the autism spectrum. First, findings indicate that, although individuals on the autism spectrum incurred a high expense in job support, by being employed, the cost to government could be alleviated in reduced receipt of disability benefits and dependency on caregivers. Second, the cost to society could be reduced in cost factors associated with community respite activities, and the welfare system if individuals on the autism spectrum were employed and receiving a regular wage. Thus, the researchers highlight the importance of employer awareness of the benefits of employing individuals on the autism spectrum. However, research conducted in their review was limited to the UK, US, and Sweden and as such do not provide a cross-national comparison of costs and benefits. Further, employment conditions and disability service systems in these countries may have since changed (Jacob et al., 2015).

Historically, studies in high school transition recognise early access to vocational education and training programs and paid work experiences implemented at the school level improved post-school employment outcomes for students with disability (see for example Hasazi, Gordon, & Roe, 1985; Kohler & Field, 2003; Test et al., 2009). A qualitative study by Trainor, Carter, Swedeen, and Pickett (2012) initiated conversations in seven communities with a focus on work-experience opportunities for adolescents with disability. Whilst participants in this survey study indicated an increased knowledge of available community resources, educating employers on the support needs of adolescents with disability was identified as a priority. More recently, research has contributed to the significance of early work experience findings of Hasazi et al. (1985), by highlighting the successes of student-participation and parental advocacy in transition planning, as well as best practices associated with transition teaching strategies (Hetherington et al., 2010; Wehman, Schall, McDonough, et al., 2014).

Within the context of work experience and employment therefore, transition planning at high school can play an important role in developing intervention programs targeting individual support needs for adolescents on the autism spectrum to ensure a seamless transition to employment (Chappel & Somers, 2010). However, given the wide scope of difficulty in individual, social, communication, and behavioural challenges in adolescents on the autism spectrum, highly individualised transition planning at the school level is necessary to address individual strengths and needs over time (Hendricks, 2010)

Transition Planning

Transition Planning and Policy

Schools have a critical role in planning and implementing interventions to ensure future success for adolescents on the autism spectrum (Chappel & Somers, 2010). In the US, the Individuals with Disabilities Education Improvement Act (2004) emphasises the importance of transition services at the school level to include transition goals to access employment, post-secondary education, and functional independence in living, for individuals with disability. As a result, federal mandating of Individual Education Plans and Transition Plans with focused goals was instituted for all individuals with disability up to the age of 16 under the Individuals with Disabilities Education Improvement Act (Baer, Flexer, & Dennis, 2013).

In Australia, there are no mandated Commonwealth laws that require educational institutions to implement individualised transition plans for students with disabilities (Commonwealth of Australia, 2014; O' Neill, Strnadová, & Cumming, 2016). Individualised Education Plans and Transition planning at the school level is dependent on individual state and school policy, and varies in educational institutions across states and territories in Australia (Dempsey, 2012; Strnadová & Cumming, 2014). However, the 1992 Disability Discrimination Act (Commonwealth of Australia, 2011) stipulates the provision of educational services for children with disabilities, and, more recently, the Disability Standards for Education (Commonwealth Australia, 2006) specify individualised planning, consultation with parents and carers', and the implementation of reasonable adjustments to educational programs for students with disability. Thus, systemic organisation of disability policy and implementation for individuals on the autism spectrum in Australia is fragmented.

Transition Planning and Schools

Transition planning for students with disabilities is a collaborative effort with contributions by a multi-dimensional team including the student, school, family, and interagency service providers (Carter et al., 2014; Davies & Beamish, 2009; Hendricks & Wehman, 2009; Trach, 2012). Strong collaboration between team members has long been seen as essential for effective transition for students with disabilities. Effective transition planning requires targeted goal setting to match individual student strengths and ability, needs, interest, and post school aspirations (Hetherington et al., 2010). Importantly, the extent to which preparation for adulthood and career awareness is embedded within planning at high school can shape skill-development, community engagement, and future aspirations for adolescents with disability (Carter, Trainor, Cakiroglu, Swedeen, & Owens, 2010). More importantly, given the empirical link of effective transition planning to post-secondary education, employment, and independent living, crafting explicit pathways to achievable adult outcomes may be perceived as a reflection of the quality and impact of transition planning (Carter, Harvey, Taylor, & Gotham, 2013; Test et al., 2009; Test, Smith, & Carter, 2014). As such, expectations of adolescents, parents, schools, and service providers must be clearly articulated as communication and collaboration between all stakeholders is key to effective planning and implementation (Carter et al., 2014).

Transition Planning and Parents

As parents plan for their child’s future, parental inclusion and contribution in transition planning meetings is crucial (Wehman, 2006). In addition, parents are important stakeholders in the transition planning process and their presence at transition meetings contributes to the development of focused goals with strategies to implement them (Hetherington et al., 2010). As parents are often primary caregivers for their children on the autism spectrum, they believe that their opinions and expectations are important (Ivey, 2004). However, parents often receive little support and their input at transition planning meetings are not always considered important (Ivey, 2004). Many families struggle to navigate access to support services after high school with some young adults experiencing a loss of support entitlements within the adult system. Consequently, the transition from a funded special education school program to the independent adult system is one that jeopardises the confidence of young adults with ASD and their families as many are in need of formal and informal supports during and after transition (Taylor & Mailick, 2014).

Best Practice in Transition Planning

Transition planning and transition services specifically for young adults on the autism spectrum are an area that is neglected in the Australian literature (Beamish et al., 2012). In one seminal study, Kohler (1996) recommends five key areas of best practice in her Taxonomy for Transition Planning, to improve post-school outcomes for students with disability. These include: (a) student-focused planning, (b) student development, (c) interagency collaboration, (d) family involvement in transition planning, and (e) program structure. Building on Kohler’s (1996) early research, several components are recently identified as necessary to a successful transition to adulthood and include specific instruction in self-determination and self-advocacy skills (Cobb & Alwell, 2009; Hendricks & Wehman, 2009; Landmark, Ju, & Zhang, 2010). A combination of these areas of best practice will be used to frame the rest of the literature review on transition planning.

Student-Focused Planning. Transition planning provides a forum for identifying student strengths, needs, and interests which allows students to make choices about their future goals and improve self-determination skills (Test et al., 2014). Indeed, according to recent research, students who participated in transition planning meetings with a main transition goal of accessing post-secondary education were more likely to participate in post-secondary education (Wehman, Schall, Carr, et al., 2014). As such, student participation at the transition-planning meeting is crucial. However, in a national longitudinal transition study, Shogren and Plotner (2012) found that adolescents on the autism spectrum had the lowest rate of participation in transition planning meetings when compared to other adolescents with a disability. In addition, the researchers found that adolescents on the autism spectrum had statistically significant higher rates of transition goals to vocational employment, functional independence, and social relationships than other adolescents with disability. Moreover, when compared to individuals with other disabilities, Shogren and Plotner found that adolescents on the autism spectrum had lower rates of transition goals of attending post-secondary education, competitive employment, and living independently. That is, in their study, adolescents on the autism spectrum had more transition support goals rather than goals associated with access to post-secondary opportunities in adulthood, such as post-secondary education and employment. Importantly, whilst support and intervention is an area of need for adolescents on the autism spectrum, Shogren and Plotner found that goals to post-secondary education and employment were not prioritised. This finding is of concern as it suggests low expectations of adolescents on the autism spectrum in being successful in post-secondary education and employment. Therefore, future research is warranted on transition planning for individuals on the autism spectrum.

Student Development. Within this transition best practice, access to paid work experience whilst at school, career education, living skills, social skills, and self-determination skills are highlighted as important (Test et al., 2009). Establishing relationships with service providers, developing rapport, and early linking at school with vocational services are recognised as important to accessing and maintaining employment after high school (Chappel & Somers, 2010). Case studies indicate that with early planning three to four years prior to leaving high school, young adults on the autism spectrum have sufficient time to work with service providers to develop skills needed for success in community access, independence, living skills, and employment (Chappel & Somers, 2010). Therefore, a combination of early transition planning and specific support and intervention at the school level are important to developing individualised skills.

Interagency Collaboration. Interagency collaboration and communication amongst stakeholders is identified as a foundation in enhancing transition program development. Indeed, according to Trach (2012), support agencies contribute their knowledge and skills of resources, community networks, and funding options during the transition planning process. In an Australian survey of 198 schools, Beamish et al. (2012) found that partnerships between schools and support agencies were problematic. It is unclear however, as to whether problems were the result of a lack of agency funding to provide school support, or whether inadequate teacher experience contributed poor collaborative partnerships with the agencies. In addition, Beamish et al. (2012) found that transition-focused program structure at the school and systemic level lacked strategic planning. Nevertheless, only interested teachers responded to the survey, thus the findings may be limited to those schools who showed an interest in the study.

In a study in Florida with 2,000 teachers on perceived levels of best teaching practice and transition programs for adolescents with disability, Lubbers, Repetto, and

McGorray (2008) found that parent and agency involvement, school policy, and communication rated as highly effective contributors to effective transition planning. However, their survey study found limited teacher knowledge of transition practices, poor focus on transition planning at schools, inconsistent systems, and policy were barriers to effective transition planning (Lubbers et al., 2008).

Self-determination Skills. Self-determination is identified as a core component of QOL and is associated with positive outcomes in individuals with intellectual and developmental disabilities (Schalock & Verdugo, 2002). According to best practice and recent research, opportunities should be provided for transition-age students to develop skills, knowledge, and attitudes to develop self-determined behaviour (Carter et al., 2013). More specifically, skills in choice making, decision-making, goal setting, problem solving, self-advocacy, self-awareness, self-knowledge, and self-regulation are associated with increased self-determination. Indeed, self-efficacy is an important construct related to self-determination, as the perseverance and resilience that individuals demonstrate influences their life choices, notably as part of the transition planning process (Canha, Simoes, Owens, Gaspar de Matos, 2016). A recent Australian study by Strnadová and Cumming (2014) examined the transition process for adolescents with developmental disabilities. Findings indicate low levels of student participation in the transition process, no recognition by schools of the student as a key stakeholder, with a lack of choice and self-determined involvement by the student. Indeed, these findings are of concern and demonstrate a lack of student-focused planning. In contrast, a study by Lee et al. (2011) found that self-determination in students with disability improved independence and QOL in adulthood. In their study, Lee et al. found that self-directed transition planning improved student self-advocacy skills with better educational outcomes.

Family Involvement in Transition Planning. Family advocacy is acknowledged on three levels of participation in meetings, engagement in transition activities, and family advocacy training to effectively engage with educators and the community (Hetherington et al., 2010). One Australian study with teachers found that transition practices across Queensland high schools acknowledged the value of parental attendance at transition meetings for adolescents on the autism spectrum with ID (Beamish et al., 2012). However, teachers in this Queensland study appeared reluctant to allow parents to collaborate or lead decision-making processes in transition planning meetings.

A second Australian study explored parent perceptions of the transition planning to post school activities for young adults with ID and young adults with Down Syndrome (Leonard et al., 2016). Most of the parents in this study were involved in the transition-planning meeting, with less than half of the young adults with ID participating. Parents also had a significant involvement in choosing work placements for their young adult child. Parents identified the need for more information about financial assistance, school transition programs, and community-based supports that would be helpful strategies for future transition planning meetings. Leonard et al. (2016) note the limited research in transition to adulthood for young adults with disabilities in Australia as the impetus for their study. In addition, the researchers highlight the likelihood of significant problems with current transition practices in Australia impacting successful transition outcomes for the young adults in their study. Moreover, the researchers identify the lack of direct consultation with young adults with ID themselves as a limitation to their study, and suggest that more research is needed in Australia, in exploring the perceptions of transition to adulthood qualitatively from the young adult themselves. Taken together, Australian research by Beamish et al. (2012) and Leonard et al. (2016) indicates a gap in transition focus specifically for young adults on the autism spectrum, and suggests a need for more research in this area.

A focus group study conducted with parents of students with disability in the US, aimed to describe parent experiences during the transition from school to post-secondary education and employment (Hetherington et al., 2010). Findings indicate that parents were dissatisfied in that they had limited involvement in contributing to transition planning for their adolescent (Hetherington et al., 2010). Moreover, parents were frustrated with lack of communication and information from the school, and constantly having to advocate for specialist services for their child. In addition, Hetherington et al. (2010) found that parents highlighted the lack of career planning and job experiences that in their perspective indicated low expectations of their children by the school. Indeed, parents noted the importance of their roles as advocates for their children, and encouraged the school to focus on the strengths and abilities of their children (Hetherington et al., 2010). Given the crucial role of parents in the transition planning process, it is therefore important to consider the role of parents and families during the transition to adulthood.

Family and Support

Parents are often the primary caregivers for their young adult children on the autism spectrum, however, there is little Australian research on family functioning and caring for their young adult children during the transition to adulthood. One Australian study by Higgins, Bailey, and Pearce (2005) found that the stress of living with a child diagnosed on the autism spectrum impacted siblings, family functioning, and family coping strategies. Aggressive behaviour was reported amongst older siblings whilst many parents emotional, mental, and physical health was impacted with some experiencing depression and anxiety. In the study by Higgins et al. (2005) parents reported feeling socially isolated due to limited understanding of ASD by family and friends. Additionally, caring for a child on the autism spectrum was demanding and left little time for other children or for parents themselves. According to Higgins et al. (2005) parents also reported that the stress associated with parenting a child on the autism spectrum impacted recreation, finances, and relationships with extended friends and family. Indeed, the Australian researchers highlight the risk of dysfunction in families with children on the autism spectrum and suggest that more Australian research is needed on parent perspectives of coping strategies.

In the US, a qualitative study conducted with families of young adults with disabilities and developmental disorders found that parent perceptions of a successful transition to adulthood focused on a person-environment fit (Henninger & Taylor, 2014). In this context, parents reported having a job or functional role in society as a priority for their young adult on the autism spectrum. However, it was important that the type of job, either paid employment, supported employment or volunteer activity, matched the needs and abilities of their child. In this study by Henninger and Taylor (2014) living away from the family home, relationships with peers, and daily living skills in cooking, managing money, and accessing transportation were also reported as desirable outcomes by parents. Within a holistic perspective, it is therefore necessary to explore the impact of ASD difficulties both on the individual and their families.

In a qualitative study with Canadian parents of children on the autism spectrum aged 2 to 23 years, parents spoke of difficulty accessing support services (Hoogsteen & Woodgate, 2013). Parents suggest since ASD is not typically identifiable by physical appearance support services for their young adult child are not deemed important (Hoogsteen & Woodgate, 2013). Indeed, research with parents of children on the autism spectrum comparing adult outcomes, indicates that although children on the autism spectrum "*looked normal*" and "*talked normal*" they never "*fitted in*" (Portway & Johnson, 2003, p. 435). This would suggest that ASD might be perceived as an invisible disability as it is not generally identifiable by physical appearance (Higgins et al., 2005). Consequently, when adolescents were overwhelmed and experienced a meltdown resulting in disruptive behaviour, parents were blamed with bad parenting for having an uncontrollable child (Hoogsteen & Woodgate, 2013). These repercussions impact access to short-term respite, due to a lack of community understandings of ASD and the perception of adolescents on the autism spectrum as aggressive and violent (Higgins et al., 2005). In turn, parents are then placed with the responsibility of being primary caregiver thus experiencing increased stress and demands in managing the physical and emotional behaviours of their adolescent on the autism spectrum. Collectively, these factors further contribute to the social isolation, physical and emotional stress, financial demands, and impaired QOL experienced by some families.

Recent research indicates there is a growing body of parent advocacy organisations with the primary objective of accessing support, sharing of information, providing input into service delivery, and ensuring policy is developed at a systems level through collaborative partnerships with key stakeholders (Koroloff & Briggs, 2006). In the US, Moodie-Dyer, Joyce, Anderson-Butcher, and Hoffman (2014) conducted interviews with parents of children on the autism spectrum aged 1 to 24 years to explore parent perceptions of ASD support service delivery. Findings indicate that parents employed several coping strategies, including making life changes, determination in seeking support, and engaging in advocacy for their children on the autism spectrum, their families and themselves (Moodie-Dyer et al., 2014). According to Moodie-Dyer et al. parents reported more negative than positive experiences in accessing support services, with collaboration, communication, financial resources, and insider knowledge rated as important. Negative experiences included lack of information in accessing resources, service providers implementing inappropriate support strategies, lack of communication between different service providers impacting quality of support, and financial challenges. Moreover, according to the researchers, service provider understanding of individual characteristics of young adults on the autism spectrum emerged as an important theme, given that access to care depended on individual variation of need with tailored support required. Specific gaps in ASD service provision identified in their study included lack of support in employment, limited or no social skills training provided, lack of community awareness of ASD, and limited or no employer education of ASD (Moodie-Dyer et al., 2014). In light of these outcomes the role of service providers is an important area to explore further.

Support Services

QOL among adults on the autism spectrum are related to formal supports that are individualised and comprehensive (Renty & Roeyers, 2006). In Australia, a variety of formal government, not-for-profit and private services are available to individuals on the autism spectrum to provide assistance in meeting daily living requirements. These services are categorised into accommodation support, community support, community access, respite, employment, advocacy, and other support (Australian Institute of Health and Welfare, 2013). According to recent data, 64% of individuals on the autism spectrum accessed community support services such as early childhood intervention and specialist therapy, 26% accessed employment services, 24% accessed respite or temporary care, 20% accessed community access services which included social skill and life skill development, and 11% accessed accommodation support (Australian Institute of Health and Welfare, 2016). Of these individuals, 73% needed supervision with self-care, 91% needed assistance with interpersonal interactions and 80% of those aged 15 and older needed daily assistance with domestic life. In addition, 84% of individuals received regular informal support from family in the areas of self-care, mobility, and communication (Australian Institute of Health and Welfare, 2016). Further, almost four out of five service users were under the age of 25. Of note is the number of individuals on the autism spectrum with unmet needs, with 39.1% requiring more assistance with communication, 22.7% requiring more assistance with mobility, and 16.2% needing assistance with self-care (Australian Institute of Health and Welfare, 2016).

According to recent research in Australia, 47% of young adults on the autism spectrum experienced a co-occurring clinical mental health condition when compared to 7% of the general population (Neary et al., 2015). In addition, in a survey conducted with adults on the autism spectrum, 70% reported experiencing mental health difficulties (ASPECT, 2013). In Australia, mental health services and disability support are structured as two separate support systems (Queensland Government, 2005). Support services for individuals on the autism spectrum and for those with an ID, is provided by the disability sector. Within the mental health service system, co-occurring mental health challenges such as anxiety and depression as experienced by individuals on the autism spectrum are perceived as part of an ASD diagnosis. As such, it is the expectation that mental health support is accessed through the disability sector. However, in many instances families and individuals on the autism spectrum report a lack of skills within the disability sector to support their mental health challenges (Australian Advisory Board on ASD, 2012). Within the current systemic implementation of services, there appears to be a lack of collaboration between the different service sectors, and as such, the infrastructure of support is limited in supporting young adults on the autism spectrum. Consequently, individuals on the autism spectrum in Australia continue to experience mental health challenges impacting all areas of daily functioning and their QOL.

Given their pivotal role in facilitating a range of services, it is surprising that a limited amount of research has been conducted from the perspectives of service providers themselves. However, there is a related line of research that examines the cost factors associated with support provision for individuals on the autism spectrum. A study by Cimera and Cowan (2009) examined the costs associated with employment services for adults on the autism spectrum in the US. Findings indicate that when compared to other disability types, individuals on the autism spectrum incurred the most expense in support services. The researchers suggest that the high cost factor may be attributed to a variety of support services needed for young adults on the autism spectrum to function effectively in the workplace. However, details of such support services are not provided in their study. Cimera and Cowan (2009) identified that although individuals on the autism spectrum were in employment, they worked fewer hours and were in low paying jobs in comparison with other disability types. In addition, service providers experienced difficulty finding appropriate job matches for young adults on the autism spectrum due to a lack of understanding of individual needs. As such, the cost factor of finding relevant work placement increased through a trial and error work placement method.

In a similar context, Jarbrink, McCrone, Fombonne, Zanden, and Knapp (2007) examined the economic impact of ASD in Sweden through interviews with young adults on the autism spectrum seeking employment support. The researchers found that the highest rate of service use was in health care with 93% of young adults accessing psychiatric services, followed by community support with 45.6% accessing daily activity centres, sheltered employment, and group home settings. In addition, parents reported providing an average of 48 hours of informal support a month, impacting the number of hours they were able to work, resulting in reduced income. Jarbrink et al. reported that the cost factor represented by employment agencies was 5%, and a loss of productivity by those young adults who had no daytime activity was 45%. The unusual low cost reported for employment services would indicate a lack of supported employment programs which the researchers suggest may have a negative impact on the economy. Indeed, findings from their study indicate the high costs incurred in supporting young adults on the autism spectrum across health systems, community care, and the provision of informal support by families. Thus, the researchers highlight that increased day care activities, informal living support, and co-occurring psychiatric conditions may be reduced if individuals on the autism spectrum are in employment, earning a wage, and engaged within the community.

Dong, Oire, MacDonald-Wilson, and Fabian (2012) investigated factors that employers, employees, and service providers considered important in making accommodations and adjustments to include individuals with disabilities in the workplace. Whilst service providers focused on the nature and extent of the disability of their client to ensure accommodation in the workplace, employers considered cost factors of supporting individuals with disability, and job performance a priority. In addition, Dong et al. reported that the support of the employee’s direct supervisor was rated as important in making reasonable accommodations within the workplace. Further, employers would consider including individuals with disabilities in the workplace if they had skills that matched the job requirement. In the study by Dong et al. employer understanding of the nature of the disability, communication between employer, employee, and service provider, and the perception of fairness in making reasonable accommodations by other co-workers, were rated as important. Whilst individuals with disabilities may be reluctant to request reasonable accommodations, collectively across stakeholder groups, communication emerged as an important facilitator of support in the workplace in their study.

A recent survey study conducted with Australian parents by Neary et al. (2015) explored the post-school service needs of young adults on the autism spectrum. Parents rated service needs in employment, post-secondary education, transition to adulthood, and social skills training as important. Findings indicate that less than 10% of young adults had their service needs met in these areas with many parents providing informal support. The researchers suggest that service provision is improved in a timely manner to meet the needs of young adults and their families. However, this study was limited to parent perspectives. The researchers suggest that future research include perspectives of young adults themselves.

Young Adult Voices

Within the international literature, studies targeting young adults on the autism spectrum are limited, with many being descriptive, based on proxy report, and focusing on multiple disability types (Browning, Osborne, & Reed, 2009; Levy & Perry, 2011; McDonald & Machalicek, 2013). Similarly, within the Australian literature, much of the information on young adults on the autism spectrum is collected in survey or interview format by proxy from parents, caregivers or teachers with limited information directly from young adults themselves (ASPECT, 2013; Beamish et al., 2012; Meadows et al., 2006; Neary et al., 2015). It is suggested that due to communication difficulties and cognitive challenges, there is limited research that has collected data directly from young adults on the autism spectrum on their perspectives of their needs and wellbeing (Gerber, Baud, Giroud, & Carminati, 2008; Saldana et al., 2009). However, recent research on self-reports found that adolescents on the autism spectrum were able to provide valid and reliable accounts of difficulty experienced in social and emotional functioning and QOL (Sheldrick, Neger, Shipman, & Perrin, 2012; Shipman, Sheldrick, & Perrin, 2011). Further, a qualitative comparison study of perceived stress between neurotypical adolescents and those on the autism spectrum found that adolescents on the autism spectrum described themselves as poor at dealing with stress regarding transition from high school (Browning et al., 2009). Moreover, adolescents indicated that stress was experienced cognitively with little or no physical signs and they would not seek support to cope with stressful situations in the future. Taken together, young adults on the autism spectrum have the ability to articulate their wants and needs, but some may be reluctant to voice their difficulties and as such, may appear to be coping with daily stresses. Collectively, given the complexities associated with the transition process in adjusting to a change of routine, loss of support structure, adapting to new social roles and responsibilities, it is important that young adults on the autism spectrum are included in future research to express their needs and experiences over their transition experiences (McDonald & Machalick, 2013; Tavernor, Barron, Rodgers, & McConachie, 2012).

Gaps in the Research

The following gaps have been identified in the literature and will be addressed in the present program of research. First, at the microsystem level, young adults on the autism spectrum and parents are recognised as key figures within the transition to adulthood process, yet their voices are missing within the body of Australian research

(Kohler & Field, 2003; Sheldrick et al., 2012; Shipman et al., 2011). Due to the limited Australian research exploring experiences of young adults on the autism spectrum directly, it is unclear what factors facilitate or limit successful transitions for adults on the autism spectrum. Differences in research methodology, ASD diagnoses and level of functioning, and limitations of existing studies call for further exploration of the transition to adulthood, particularly by listening to the voices of young adults themselves. Study 1 is proposed to fill this gap in existing knowledge and to provide a rich description of transition experiences. Semi-structured interviews will explore both young adult experiences in Study 1, and parent perspectives of the transition to adulthood in Study 2, to identify specific factors relevant to the transitions of young adults, and to inform the development of Study 3. Study 3 will build upon the outcomes and themes gathered in Study 1 and Study 2 to further explore factors that impact successful transition to adulthood in a longitudinal case series study.

A second gap identified in the literature is the limited knowledge of Australian service provider experiences of transitions to adulthood. At the macrosystem level, disability service providers play a complex role in facilitating a transition to adulthood for young adults on the autism spectrum in providing links to appropriate services. However, it is during this pivotal stage of transition that many young adults lose structure and supports associated with the school support system (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). As such, it is unknown how service providers are positioned in interacting with young adults as they exit high school and access the adult disability system. Therefore, Study 4 will address this gap in knowledge by providing a comprehensive overview of successes and challenges during the transition process from the perspective of disability support providers.

Significance of the Study

Collectively, the increase in autism prevalence in Australia is comparative with prevalence rates in the international literature. What must be noted however, in response to poor post-school outcomes in individuals with disability in the US, there has been ongoing research, planning, and funding since the early 1980’s (Kohler, 1996; Kohler & Field, 2003), compared to a lesser degree in Australia since the 1990’s (Meadows et al., 2006). As a result, in the US, federal mandating of Individual Education Plans with focused transition goals was instituted for all individuals with disability up to the age of 16 under the 1990 Individuals with Disabilities Education Act (Baer et al., 2013). As such, research indicates that to some degree, with early transition planning, family support, and interagency collaboration at the school level, young adults on the autism spectrum can be successful in transitioning to areas of post-secondary education, employment, social interaction, and independent living (Adreon & Durocher, 2007; Barnhill, 2016; Chiang et al., 2012; Wehman, Schall, McDonough, Kregel, et al., 2014).

Early research into transition practices for Australian individuals with disability was conducted in the 1990’s, funded by the New South Wales Department of Education (Parmenter & Riches, 1993). Findings indicated eight core features of transition planning for young Australians with disability in; a commitment by governments to central policy, individual transition planning by a multidisciplinary team, relevant curriculum and instruction, vocational options after high school, links to post-school options, professional development, community involvement, and interagency collaboration (Riches, 1996). Whilst Parmenter and Riches (1993) view their research findings as agents of change at the time, little has since been done by the Australian Government to formally structure transition support for Australian individuals with disability (O’Neill et al., 2016).

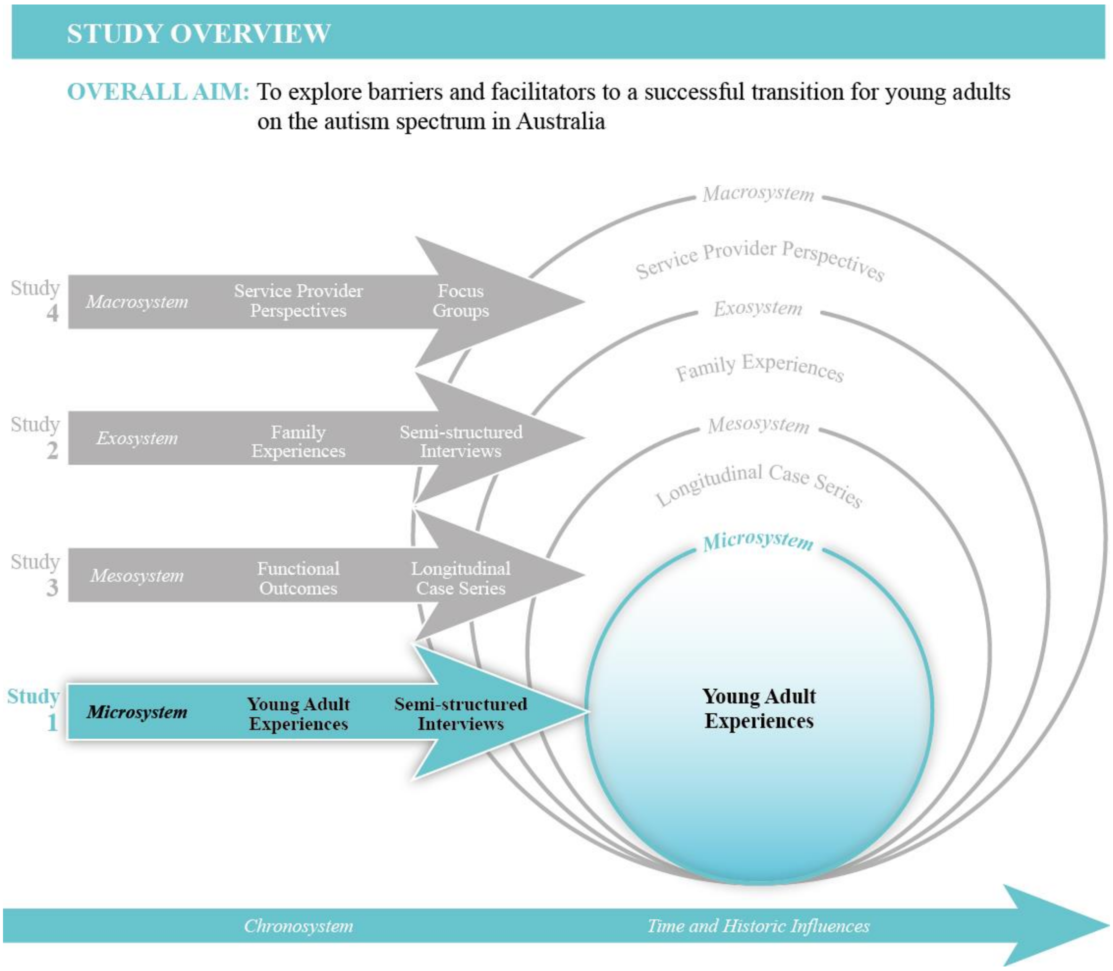
Although there is an emerging body of research with young adults on the autism spectrum in Australia, much of the transition research is limited to government and non-government reports, proxy reporting, surveys, and research with multiple disability types (ASPECT, 2013; Beamish et al., 2012). To date, Australian research has failed to examine whether the combination of recommended *transition best practices* in the international literature is predictive of adult outcomes in multiple domains specifically for young adults on the autism spectrum (Kohler, 1996; Kohler & Field, 2003). As discussed earlier, one Australian survey study provided an examination of demographic, individual, and group characteristics on how young adults with ASD experience transition (ASPECT, 2013). However, this survey study included adults within the broader age group of 18 to 70 years old, many having surpassed young adulthood, and some of who were self-diagnosed as being on the autism spectrum. Another government-funded project investigated the relationship between transition practices and post-school outcomes for students with disability in government and non-government schools in Australia (Meadows et al., 2006). Findings of this research project indicate transition practices in the areas of program structure and interagency collaboration were problematic at schools, with transition goals in employment, community access, and social interaction omitted in planning for many of the students (Meadows et al., 2006). However, there has since been little progress in follow up studies for individuals on the autism spectrum. Indeed, there has been a lack of transition outcomes studies for young adults on the autism spectrum documented in the recent Australian research literature (Leonard et al., 2016; Strnadová & Cumming, 2014).

Since the early research conducted by Parmenter and Riches (1993) there are inconsistencies in Australian disability policy and transition planning for individuals on the autism spectrum. Yet, consistent with outcomes in the international literature, Australian young adults on the autism spectrum perform poorer in post-school outcomes than neurotypical peers (ABS, 2016). This highlights an important point for consideration in Australian disability policy and infrastructure. That is, it may be the case that Australian young adults on the autism spectrum would benefit from ongoing research and structured disability policy implementing mandated individual transition plans, transition services, and funding consistently across the newly implemented NDIS. Notably, by asking young adults on the autism spectrum what they consider to be positive and negative experiences during the transition period could provide insider perspectives into what are the successes, and what are the challenges for young adults currently at the very centre of the transition process. Such information is of importance to inform evidence based practice to a wide audience, including policy developers. Therefore, it is imperative to investigate factors that would facilitate or inhibit a successful transition to adulthood, specifically for young adults on the autism spectrum, to enable focused transition goal planning at high-school; to inform program development for agencies supporting these individuals both during and after high school; to provide families with a disability infrastructure that is accessible, to improve QOL for these individuals, and to reduce dependency on the state welfare system. More importantly, as Australian disability infrastructure is currently undergoing reform with the implementation of the NDIS, this study is timely and relevant. It is anticipated that a major contribution of this program of research will provide autism specific knowledge to strategic policy development with a focus on young adults on the autism spectrum, their parents, and service providers who support them.

Summary

This chapter presented a review of the literature on factors associated with the transition to adulthood in the extant literature. The theoretical framework underpinning this body of research, Ecological Systems Theory (Bronfenbrenner, 1994) was introduced, followed by ASD prevalence and current implications within a systems perspective. Further, the role of families, transition planning, and support services was examined in detail with regards to their positions within the transition journey to post-secondary education, employment, independent living, social interaction, and overall QOL. The next chapter, Chapter 3, will present the analysis and findings from semi-structured interviews with young adults on the autism spectrum, conducted in Study 1.

Chapter 3 – Study 1: Voices of Young Adults



STUDY OVERVIEW

OVERALL AIM: To explore barriers and facilitators to a successful transition for young adults on the autism spectrum in Australia

Figure 3.1. Flowchart summarising Study 1, young adult experiences within the microsystem.

Background

There is general consensus in the literature as discussed, that individuals on the autism spectrum have poor outcomes in key adult roles of post-secondary education completion, competitive employment, and independent living when compared to neurotypical peers (ABS, 2016; Henninger & Taylor, 2013). As such, these individuals pose an increased dependency on the health and welfare system, on their families, and the community (Synergies Economic Consulting, 2011). There has been a large amount of research on individuals on the autism spectrum collected in survey or interview format by proxy from parents, carers, and teachers (Browning et al., 2009; Levy & Perry, 2011; McDonald & Machalicek, 2013). Indeed, as discussed previously, parents play an important role in the lives of individuals on the autism spectrum, and as such, their perspectives of their young adult children's experiences are important. However, listening to the experiences of young adults in their own voices, their individual ways of communicating, and their areas of focus on things that are important to them, provides invaluable information to inform evidence-based practice to a wide audience. Nevertheless, some researchers suggest that because of communication, social and cognitive difficulties typically associated with ASD, a limited amount of research has focused on asking young adults on the autism spectrum directly about what their wants and needs are as they transition to adulthood (Gerber et al., 2008; Saldana et al., 2009). On the contrary, research indicates that individuals on the autism spectrum with average to above average intellectual ability are able to articulate their social and emotional needs, and have strong opinions about what works for them and what doesn't (Hurlbutt & Chalmers, 2004; Sheldrick et al., 2012; Shipman et al., 2011). Therefore, asking individuals on the autism spectrum about their transition experiences will provide an insider perspective on the wants and needs of young adults in Australia, and provide first hand information to developing effective service provision across multiple ecological systems. This chapter will explore, describe, and interpret the transition experiences to adulthood by listening to the voices of young adults on the autism spectrum. The present study strengths and limitations, implications of findings, and future research directions will be discussed in the general discussion in Chapter 7.

Significance of the Present Study. This study presents a paradigm shift in focus from traditionally speaking by proxy for individuals on the autism spectrum to speaking directly with them by listening to their lived transition experiences.

Therefore, within the microsystem, in listening to the voices of young adults on the autism spectrum, the present study explored the successes and challenges of life experiences underpinned by Bronfenbrenner's Ecological Systems Theory (1994). The purpose of this phenomenological research was to explore young adult experiences to independent living, friendships, post-secondary education, and employment. The research question that guided this exploratory study was: *What are the experiences of young adults on the autism spectrum during the transition to adulthood?*

Method

Qualitative research using semi-structured interviews was chosen to allow for an in-depth investigation and broader understanding of the lived transition experience, thus identifying specific factors relevant to young adults. Interpretative Phenomenological Analysis (IPA) was used to analyse the interview data (Smith et al., 2009). IPA is a qualitative research approach that aims to gain an understanding of an individual's perception and lived experience of a particular event (Smith et al., 2009). In planning and conducting the present research, I paid careful attention to guidelines regarding methodological rigour (Lincoln & Guba, 1985; Morrow, 2005; Yardley, 2008). The use of the first person is indicative of my transparency in a coherent presentation of the systematic IPA methodology that I employed throughout my research journey (Yardley, 2000).

Transition planning is largely a multifaceted phenomenon involving systemic interaction between personal, social, and environmental factors. IPA is particularly suited to understanding the chain of connection between young adults embodied experience, socio-emotional reaction, and sense making of the transition to adulthood process. As such, within a systems perspective, the psychological focus, and personal meaningfulness of the transition process will vary depending on the individual, school, family, and socio-cultural contexts.

Recruitment

Ethics approval was granted from the University of Southern Queensland's Human Research Ethics Committee prior to recruitment (USQ: No. H15REA227). Participants were recruited through ASD support organisations and the researcher's networks. The Participant Information Sheet (Appendix A) was e-mailed to Autism Spectrum Australia, Autism Co-operative Research Council, Asperger's Australia, and advertised on parent, and community Facebook groups. Participants who were interested contacted the researcher and were then e-mailed a consent form. Inclusion criteria were that young adults were between the ages of 18 to 25, have a formal medical diagnosis of ASD without ID, currently experiencing transition, and live in Australia.

Participants

Participants were young adults on the autism spectrum aged 18 to 25 living in Australia. Guided by Smith et al.'s (2009) recommendations on the sample size for a Doctoral thesis, four young adult participants were interviewed. Whilst maintaining a commitment to the idiographic nature of IPA, having four participants allowed for a rich depth of analysis of similarities and differences between individual experiences (Willig, 2013). Participants were provided with the opportunity to select a pseudonym and were informed that all identifying information would be changed. Table 3.1 presents a summary of participants' key demographic information.

Table 3.1

Study 1 Participants' Demographics

Young Adult	Gender	Age	Education	Employment	Living Circumstance	Age of Diagnosis	Transition Support
Casper	Male	25	College Diploma	Full-time	Family	6 years	Yes
Coby	Male	24	Currently at University	Part-time	Share home	15 years	No
Mike	Male	18	Vocational Education Certificate	Volunteer	Family	7 years	Yes
Jade	Female	22	Currently at University	Part time	Share home	21 years	No

Interview Procedure

Informed consent was gained prior to the interview (Appendix B). Semi-structured interviews were conducted to gather personal appraisal of experiences to independent living, post-secondary education, employment, friendships, and overall life satisfaction during the transition to adulthood (Smith et. al., 2009). Participants were informed that interviews would be recorded and all information would be confidential. Participants were provided a choice of telephone-interview, online chat forum, written response or face-to face interview. These were considered appropriate methodological options due to their flexibility in terms of geographical location and time imposition. Previous research reports these methods as being less intrusive to families and individuals on the autism spectrum, avoiding face-to-face contact that may be challenging for some individuals (Eaves & Ho, 2008). Casper, Coby, and Jade were interviewed face-to-face, and Mike chose to be interviewed by telephone. Participants were e-mailed questions prior to the interviews to facilitate comfortable communication and ease any possible anxiety. Questions explored participants' experiences with support at school, family support, disability support services, post-secondary education, social interaction and the impact of ASD on the transition journey.

My interview technique was based on empathic understanding and semi-structured interviews were used to facilitate rapport with participants (Smith et al., 2009). For example, the opening question "*Can you tell me a little bit about yourself; for example, what is it like to be on the autism spectrum*?" was used as an icebreaker to build rapport with participants. Interview questions were largely open ended to elicit in-depth meanings, for example:

- How do you feel about the support you received at high school in preparation for life after high school?
- What was your relationship with your family like during the transition process?
- How do you feel about your ASD and the impact on your ability to access employment, to pursue tertiary study, to friendships, to partners?

In IPA, an interview schedule of questions is used to prepare for the likely content of the interview, facilitates the discussion of relevant topics, and allows the researcher to set a flexible agenda (Appendix C). This schedule allows for the research question to be answered subsequently through analysis (Smith et al., 2009). As such, I developed a flexible interview schedule with my supervisors, and open-ended questions were incorporated including prompts if further details were required (Yardley, 2008). I engaged in participant checks during the interview to clarify my understanding of the issue with brief follow-up questions (Kvale, 1996). Participants were interviewed individually for 45-60 minutes each, in mutually agreed locations, and interviews were recorded on a Zoom H2 Handy Recorder. Participants were informed that transcriptions of the interview would be made available to ensure transparency, credibility, trustworthiness, and participant validation (Willig, 2013).

Data Trustworthiness

As IPA is steeped in interpretation, authenticity and transferability in the presentation of original interview quotes, and thick descriptions ensured qualitative rigour (Cohen et al., 2000; Lincoln & Guba, 1986). In presenting relevant interview quotes with rich interpretations, the reader is provided with a context to determine accuracy in transferability to similar contexts associated with their own situation (Cohen et al., 2000; Lincoln & Guba, 1986). Credibility of findings was demonstrated by lengthy and intensive engagement with participants during interviews that lasted between 45-60 minutes, whilst ensuring a level of ease and comfort for the participants. At the end of each interview, member checks were conducted with each participant to verify the accuracy of information provided in response to questions asked during the interview (Creswell & Miller, 2000).

Transcripts were reviewed separately by the researcher and both supervisors to ensure independent analytical checking (Lincoln & Guba, 1986). Based on the initial coding, transcripts were reviewed several times and were subjected to 6 months of intensive coding and refinement. Of the four participants interviewed, two participants engaged in a second round of member checking of interview transcripts. Both participants agreed on the information in the transcripts with one participant adding more detail. Finally, to ensure confirmability of the findings, IPA methodology and associated hermeneutic phenomenological contexts were captured in explicit detail as outlined in Chapter 1, to support the qualitative analytic approaches chosen in this study (Lincoln & Guba, 1986).

Data Analysis

Interviews were transcribed verbatim following recommendations for transcription for IPA by Langdridge (2007). The analysis closely followed the four-stage process described by Smith et al. (2009). During the first stage, I engaged with the data through listening to the recordings and reading and re-reading the transcripts to become familiar with participants' responses (Willig, 2013). Once immersed within the data I began annotating my initial exploratory comments in the right margin based on specific ways participants spoke, thought, and understood issues associated with the transition process. I reflected on my initial analysis with my supervisors who reviewed and commented on my initial codes. I then re-read the transcripts with a focus on the linguistic tools and metaphor used to colour participants voice as they spoke of important things that made up their lived transition experience (Willig, 2013). For example, when Casper spoke of his "*autism as a gift*" (Casper, 346), a deeper interpretation alluded to his positive attitude in accepting the challenges that were part of his ASD.

During the second stage, whilst staying close to participants' personal perspectives, I re-read individual transcripts to discover emergent patterns that I then noted in the left margin (Smith et al., 2009). I approached each transcript as an individual case and was sensitive to specific nuances, differences, and commonalities that brought participants experiences to life (Elliott, Fischer, & Rennie, 1999). For example, throughout the interview with Coby, a recurrent theme of loneliness and isolation was interwoven in his responses. I looked for echoes of ideas and areas of tension as my analytic attention moved from individual cases to the shared experience across cases (Eatough & Smith, 2008). For example, in Jade's responses, her comments on lack of friends were closely linked to Coby's sense of loneliness and isolation.

During the third stage the themes were further explored in order to make connections between them. For example, with Coby and Jade, a link across cases resulted in a subtheme of social interaction. As emergent themes were identified I grouped them into higher order categories and superordinate themes were determined based on the frequency that they occurred across cases (Willig, 2013). For example, acknowledging the challenges and difficulties associated with being on the autism spectrum emerged in conversation with all participants. Thus, the importance in presenting their shared understandings of how ASD impacted their life-world was captured in the superordinate theme of *Embracing ASD Differences*.

During this third stage my supervisors again reviewed and edited themes to ensure they were grounded and well represented in the interview transcripts. My supervisors and I engaged in regular dialogue about the coded data and what this might mean for the participants within the transition context. Following analysis of individual transcripts, patterns were coded across transcripts. In the fourth stage, IPA analysis of the data resulted in an overarching of four super-ordinate themes within which were nested the subthemes relevant to young adult’s lived experiences of transitions to adulthood.

Findings

The four main themes resulting from IPA analysis were *Embracing ASD Differences, Social Interaction, Employment,* and *Functional Independence*. Although these themes are presented distinctly, they are interwoven in forming the experiential understanding of participants. The four superordinate themes and their components are presented in Table 3.2 below.

Table 3.2

Themes Emerging from an Interpretative Phenomenological Analysis of Interviews with Young Adults on the Autism Spectrum in Study 1

Theme	Theme Title
Theme 1	Embracing ASD Differences • Understanding their ASD differences • Secondary Difficulties and their Impact
Theme 2	Social Interaction • Friendships • Communication
Theme 3	Employment • Access to Employment • Family Advocacy in Seeking Employment
Theme 4	Functional Independence • Family Support • Self-advocacy and Success

Theme 1: Embracing ASD Differences

The four participants interviewed ranged both in age and life experience, from straight out of high school (e.g., Mike aged 18) to having lived independently and having several employment experiences (e.g., Casper aged 25). To some extent, this age continuum provided a comparison of different experiences of transitions and life expectations over time. Jade, Coby, and Casper offered in-depth insights in overcoming personal hurdles, whilst Mike's responses to interview questions were short phrases without descriptions. He did however respond to further questions and prompts.

Understanding their ASD Differences

All participants acknowledged facets of their ASD that presented challenges in daily life interactions. For instance, Jade reflected on her need for structure and routine, which is a theme that emerged throughout our interview. The influence of her rigidity permeated all aspects of Jade's daily-lived experiences:

> I think it was just losing structure really just - I was just probably a mess for a couple of months after leaving high school…I kind of felt like I wasn't really achieving anything or doing anything with my life…If I don't have structure, if I don't have something I need to - if I don't do something productive every day I feel like I'm not achieving anything (Jade, 51-59).

Here Jade accentuates the links she perceives between structure and her ability to be successful. Her tone is emphatic suggesting potential discontent if her routine is disrupted. Mike echoes Jade's need for routine as he describes his daily ritual below:

> Get up, get dressed, feed the dog, have my breakfast, have my medication, brush my teeth (Mike, 153-154).

Mike's response here appears short and sharp, and would suggest that the daily routine described in the quote above is one that he is accustomed to, and dependent on for his daily functioning.

Another point of conversation is the difference within the social realm and the notion of fitting into a peer group that reverberates between Coby, Casper, and Jade. These participants reflect on early difficulties socialising at school in an attempt to make sense of their feelings of loneliness and isolation. Below is Coby's reflection:

> We were just the people didn't really fit in elsewhere. So, we were always like that. We didn't really come together because we were super interested in each other. Basically, because we were all alone, be alone together (Coby, 66-72).

Coby acknowledges that it was his differences that set him apart from peers in high school. Whilst he was part of a group of others at high school who also did not fit in, his tone is melancholic as he speaks about still being alone within the group.

Similarly, Casper mentions this viewpoint as he wrestles with his early difficulties in socialising:

> I think the biggest challenge was I suppose more the socialising and just having trouble comprehending why - even though I knew about my autism from an early age I think it was just more comprehending why I had so much difficulty socialising with other peers (Casper, 101-105).

In a similar vein, Jade’s thoughts resonate with Casper as she discloses a life of dealing with confusion regarding the issues she faced in trying to fit in with peers:

> I think being diagnosed gave me a ticket to just be me… I've always kind of filtered a lot of Jade out to try and fit in with other people, to try and connect with other people and relate with other people. I've kind of dulled my own personality to be more like others whereas when I got diagnosed. I'm like well I've got a piece of paper that explicitly says that I'm not the same as everybody else, why should I even try anymore, so I stopped trying (Jade, 124-131).

Jade’s tone highlights her initial desperation in wanting to feel included and be part of a peer group. However, her diagnosis at age 21 provided her with an insight into her unique identity and gave her a sense of freedom to be herself. She appears to be comfortable and sounds positive in accepting her ASD differences.

In a similar vein, Casper reflects on his ASD:

> I suppose seeing my autism as a gift. Just understanding what it's like seeing things in a different point of view…that people don't get to see, and just try and use that to my advantage to I suppose help to improve myself (Casper, 346-351).

When compared to his earlier struggle in understanding difficulty socialising with peers at school, it is as though Casper experienced a later life-changing vision in embracing his autism with a positive and accepting attitude. Both Jade and Casper’s voices reflected a release of tension as they allowed their individual ASD identity to emerge. Both acknowledged that as they got older, they were able to recognise differences within themselves from neurotypical peers. It seems as though both Jade and Casper harnessed the differences that surfaced through their ASD, and embraced their newfound identity with an enlightened perspective. For Jade and Casper, embracing their ASD differences provided an insight into their unique personalities. However, Coby’s difficulty with loneliness is a motive that he returns to throughout the course of our interview.

Secondary Difficulties and their Impact

The young adults interviewed were spontaneous in their acknowledgement of the impact of anxiety, depression, low self-esteem, poor attention and concentration, in making sense of their transition experience to adulthood. It is likely that because all participants have average to above average intellectual ability, they are cognitively able to recognise their differences and incapacities in daily interactions, and are therefore more susceptible to low self-esteem, depression, and anxiety (VanBergeijk et al., 2008; White, Ollendick, Scahill, Oswald, & Albano, 2009). Coby expressed concern over depression impacting his ability to achieve academically at a similar level of his peers in high school. Casper echoed Coby’s concerns and highlighted ongoing challenges he faced with low self-esteem, intermittent periods of depression, and social anxiety. Jade experienced anxiety with the change of structure and routine in transitioning to university whilst Mike experienced ongoing difficulty remaining focused with activities on a daily basis.

Casper’s low self-esteem emerged immediately after high school, and continued to echo in his late stage of the transition process at the age of 25. As he articulates:

> When I finished high school, I had a bit of low self-esteem and I did a horticultural course through college [ABC]… I was a little bit uncertain and I had trouble with communicating and socialising with others (Casper, 35-40).

In addition, Casper expressed anxiety at the thought of life after high school, particularly with socialisation:

> I think I was concerned I wouldn't be able to hold the friendships that I had in high school and I was a bit - I remember being a little bit uncertain what the future held… so I had a bit of advanced social anxiety (Casper, 31-34).

Casper’s recount of tenuous friendships and low self-esteem is a theme that is interwoven throughout our interview. For Coby, it would appear that he stumbled upon his ASD diagnosis whilst being treated for depression at the age of 15. Compounded with treatment for epilepsy, Coby's high school years were difficult:

> Also, I was relatively promising in Year 10, early Year 11 kind of time. I dropped off towards the end and I don't think I really achieved what I could have done. …It could have been the medications, but it probably also had a bit to do with the autism (Coby, 40-44).

Coby appears conflicted as he reflects on his struggles in coping with the academic demands of high school. Whilst he believed he was academically capable, when compared with his peers, there seemed to be a barrier preventing him from being successful. He questions as to whether this was because of his depression, his ASD, or the medication to treat his mental health. On the contrary, Jade believes it was her academic ability that assuaged her stress and anxiety and facilitated a somewhat smooth pathway in high school:

> I was very smart, very smart. That kind of helped but in terms of challenges. I think I took school extremely seriously so I was often very anxious, very stressed (Jade, 18-23).

Here Jade's emphasis on her academic ability alludes to the possible demand and high expectation she has of herself. Therefore, her reference to "*often anxious*" suggests an underlying innuendo of angst in the event of failure at meeting these self-imposed high expectations. Whilst his responses during the interview were punctuated with phrases, Mike did acknowledge limitations in his ability to remain focused, and how this impacts his daily activities:

> My dad drops me off and picks me up [Do you plan to get your licence some time?] No. Distracted too easily (Mike, 101-105).

In this brief recount, Mike is dependent on his father to drive him to and from his daily activities. His response is short and sharp as he acknowledges his distraction in attention as a barrier to getting his driver's licence. The ramifications of both

Mike’s inattentive behaviour and lack of a driver’s licence may have consequences for his future career pursuits.

Summary

In summary, all participants recognised the existence of social-emotional or mental health difficulties and questioned the impact it had on their daily life activities. It is suggested that because individuals with average to above average intellectual ability are more able than individuals with other disabilities, they experience distress by their social incapacities, and are susceptible to anxiety, depression, and low self-esteem. For instance, it is suggested that anxiety occurs because these individuals are cognisant of their difficulty in social interactions, that depression occurs because of the stigma linked with social difficulties, and collectively, that low self-esteem emerges because of a combination of these difficulties (Ghaziuddin et al., 1998; VanBergeijk et al., 2008). Casper found a sense of enlightenment in embracing his ASD as a gift, whilst Jade’s diagnosis was her ticket to freedom in accepting her real self. Coby struggled with loneliness and depression, whilst Mike was despondent as he spoke about his short attention span and the impact of this on his ability to gain a driver’s license.

Theme 2: Social Interaction

Individuals on the autism spectrum experience challenges in social interaction throughout the lifespan; however, the period of adolescence-to-young adulthood is particularly socially demanding in establishing and maintaining friendships (Duncan & Klinger, 2010). Some of the young adults interviewed expressed a desire to have friendships, to increase social networks and engage socially with peers. In some experiences, it would appear that family members fulfilled these social needs. For example, Coby’s weekend socialising revolved around visits to his grandparents’ home, going to the movies, and having a cup of coffee with his mum, whilst Mike's regular Sunday socialisation activity was focused around going to church. Jade preferred to limit her social activities with friends and it took Casper many years after high school before he joined a gym and established a friendship.

Friendships

It is known that young adults on the autism spectrum lack friendships, however, the reasoning behind this perception is somewhat intricate. Whilst young adults on the autism spectrum desire friendships, the challenge in understanding social etiquette, interpreting body language, and decoding non-verbal cues present a limitation in establishing friendships (Duncan & Klinger, 2010). For example, Casper experienced initial difficulty forming friendships after high school:

> It took me a while to form some friendships through the early years. Then I made a few friendships later on. After high school, it took me a number of years - until I finally went to a gym and I had a personal trainer who became a really good friend to me (Casper, 27-29).

Here Casper's reflection is twofold. On the one hand, it might be the case that the difficulties of adolescence presented challenges for Casper to form friendships. On the other hand, it might be facets of his ASD that presented hurdles in making friends. Jade's experience is similar, where, for the first two years at university, she had no friends:

> I've always wanted to connect with people to some extent but I never really knew how to (Jade, 100-101).

Jade now has a few friends that she chooses to socialise with occasionally:

> Social activities with peers…I would say no. It gets a bit overwhelming because I'm used to just having a few select friends in the sense that - which means that I can kind of go off the radar and just be antisocial for a whole month (Jade, 504-521).

In this recount Jade appears to be conflicted. There seems to be an underlying tension between the idea of having friends and the stress of the experiential process involved in talking to and interacting with people. It might be that the inherent peer pressure of being part of a social group is appealing, however, the demands of interaction and communicating are overwhelming for Jade. It is likely that having a few friends who are understanding of her differences in social interactions, will allow Jade periods of quiet time without feeling obligated to maintain regular social niceties. It is almost as though Jade is attempting to forge a balance between managing her difficulties in social interactions with a select group of friends who understand her and who probably will not be offended when Jade chooses to have some down time.

In a similar vein, Coby acknowledges that as a young adult he misses social interaction:

> Right now, I'm thinking that I probably want to branch out and find a few more people that I can do friend stuff with. Mostly my social stuff is a bit more I guess surface level. It's not going to an event together or having coffee or whatever, in lots of ways that kind of role was filled by mum (Coby, 331-336).

In addition, Coby reflects on intimate relationships:

> I suppose another one is more intimate relationships. I've not had them at all and that's kind of hard considering I'm 24. It's like I probably should have had at least one by now (Coby, 401-404).

In their reflections, it is apparent that Jade, Casper, and Coby struggle with friendships. It might be the case that Casper's insight into his "*autism as a gift*" (Casper, 346) gave him the self-confidence to seek and form friendships. Similarly, Coby reflects on his need for a partner and acknowledged his ongoing difficulties in socialising with peers. His experience is:

> I suppose probably something else that's quite difficult for me is the loneliness so it's become bigger more recently. I obviously recognise that earlier on when I'm thinking okay I want to go on campus specifically because I need to meet people and do stuff with them. But lately as contact with friends has become even less…I'm really trying to find friends and people that I can get along with (Coby, 394-400).

In an attempt to increase his social networks Coby changed his mode of study from an external student to an on-campus student. He has joined several social groups at university and believed this will allow him to access social networks and friendships.

On the contrary when asked about his friendships, this was Mike’s response:

> [Do you go over to any friends' places?] No. [Do you have any of your mates over?] No. Well, extended family but that's about it, Sunday, go to church (Mike, 70-74).

Here it would seem that Mike has lost contact with peers from high school and lacks friendships at the moment, but he doesn’t appear to be particularly concerned. His socialisation appears to be with extended family members and attending church on a Sunday.

Communication

Young adults on the autism spectrum experience difficulty initiating and reciprocating conversation, understanding humour, and interpreting emotions (Barnhill, 2007). Sometimes, miscommunication may be viewed as intentionally inappropriate, rather than a characteristic of the condition (Attwood, 2000). Whilst Coby is proactive in seeking friendships, he experiences challenges in communicating with peers:

> I've had situations where I'm not particularly good at social stuff and I've done some weird things. From that, I've held back quite a bit. Generally speaking I'm pretty quiet. Even in the more social things that I purposefully do like the Student Representative Council for example, I'll sit in a meeting and I won't talk until one or two points are important but hasn't been said by the other people (Coby, 344-349).

Cognitively, Coby is astute in his recognition of important points to be mentioned at student council meetings. However, it would seem that he bears the scars of previous unhappy social episodes as he refers to “*some weird things*” that impact his contribution at these meetings:

> An example was I met some people when I was doing my previous degree in commerce. They told some kind of story and it wasn't exactly super appropriate for every situation. But the way that they were talking about it, it was fine by them. They weren't that concerned about how other people might think. So, when I mentioned that later on because of some other situation that was sort of relevant, they got a bit annoyed (Coby, 354-360).

In the quote above, Coby is keen to fit in and maintain friendships but does not appear to understand the social nuances and rules, in this instance keeping the conversation privy to that particular social group. It is likely that due to his neglect of social skills in knowing what to say, and when to say it, his behaviour as perceived by others is inappropriate. He mentions his limited interactions:

> Yeah, in retrospective, I was probably quite isolated. It didn't really affect me a whole lot for whatever reason. I was occupying myself with various things. I think I was doing a fair bit online gaming…I guess I was just distracted from reality because obviously I wasn't really talking to people on a regular basis, like outside the family on a regular basis (Coby, 436-441).

Coby reflects on his loneliness and isolation and mentions that his conversations are limited to family with brief interactions with others. Similarly, Jade mentions that, "*I can just go a whole month without talking to anyone and it's fine*" (Jade, 513-514). There appears to be a tension between Coby's keen desire for friendships, and a limited understanding of social niceties and interaction, which presents a barrier to progressing friendship formation.

For Mike, his biggest challenge after high school was, "*Well missing some of my friends. I miss talking*" (Mike, 81). Mike's tone is despondent as it would seem his social interactions and communication is limited to immediate and extended family. Through a different lens, Jade mentions that she sometimes feels silly asking her lecturers to explain abstract language that might be used in lectures:

> If I have to ask a lecturer what does it mean to jump in the deep end or what do you mean something's hamstrung? There's no ham. There's no pig. You're talking about psychology, I don't understand (Jade, 284 -287).

Here Jade is confused as she does not understand the reference to, and relevance of "*hamstrung*" in a psychology lecture. In her minds-eye, she associates "*hamstrung*" with ham, and ham with pig. It is known that individuals on the autism spectrum have difficulty decoding the use of metaphors, as they think in literal terms (Happé, 1995). In this quotation, it can be seen how everyday communication incorporates many different ways to construct meaning, one of which is through inferences. Understanding these connotations is an area that individuals on the autism spectrum have great difficulty with, as can be seen by Jade's literal interpretation above.

Summary

In summary, all participants expressed a desire to access friendships. At the same time, they recognised their difficulties in communication and social interaction. During adolescence, social interactions are key to a range of different types of relationships such as social club inclusion as well as popularity amongst peers (Wehmeyer, Shogren, Zager, Smith, & Simpson, 2010). Indeed, according to Tobin et al. (2014) it is not the case that adults on the autism spectrum are resistant to social interactions and friendship formation; rather, difficulties with pragmatic language, an inability to provide the appropriate information at the right time in conversations, an inability to understand nonverbal cues, or a tendency to translate information literally, pose a barrier for them. As such, Jade acknowledged her desire to have friends, but at the same time restricted the frequency and intensity of her social interactions possibly in an attempt to make face-to-face encounters and conversation more manageable. Whilst Coby made a choice to be on-campus to participate in social activities, difficulties in social interaction failed to assuage his feelings of loneliness. He reflected on his perceived normative development as a young male, and missed not having a partner. For Casper, challenges with low self-esteem and difficulties with communication permeated his friendship formation and escalated his social anxiety. Whilst Mike's interview responses were short and direct, he acknowledged missing talking to friends from high school.

Theme 3: Employment

Accessing and maintaining paid employment is a significant contributor to achieving successful adult milestones (Gerhardt & Lainer, 2011; Halpern, 1985; Roux et al., 2013). Success in the workplace and financial stability are normative adult challenges associated with transitioning to adulthood. All participants received formal or informal support to access employment, however, their experiences of the workplace differed. Casper experienced support from a range of disability employment services extending from work experience placements during high school, to part-time paid employment after high school. Mike received support through disability service providers within the community to access respite and occasional volunteer work, whilst Coby and Jade received support from their family to access employment.

Access to Employment

Casper's initial work experience was as a cleaner at a bowling alley. At the end of high school, he was offered a cleaning job at the bowling alley:

> I turned down the job at the time because…I was just finishing high school and I think I wanted to do something a wee bit more like…something with computers but I wanted to do something that would lead me into a career (Casper, 297-302).

Casper's reference to, "*a wee bit more*" provides an insight to his perception of his work capability, that he is capable of work that is more stimulating than being a cleaner, and possibly one that will lead him into a career pathway with computers and technology. After several job placements, he believed his communication difficulties and anxiety impacted his access to long-term employment:

> Then I kind of felt that just the people I was with seemed to put limitations on me a bit. They did a few things like cut my hours …they said I was making a few mistakes. But I felt at the time that I was being treated differently through the job (Casper, 57-61).

In Casper's view, he was being punished for being different, that the employer was not accommodating of his specific needs and this impacted his hours of work and his pay. For the past five years Casper has worked for 2 hours a day. At present, he has had an increase in his work hours to 5 hours a day, 3 days a week:

> When I was doing two hours a day I felt that wasn't enough… Then when I moved onto the five hours I started to enjoy it. I just feel the purpose to work and feel part of the team. Yeah, I've got work friends there…working with the full timers, like I seem to get along with everyone there and that makes a big difference. I think that's helped boost my confidence up as well (Casper, 265-278).

Here, Casper sounds elated as he is part of a team, he feels valued and his self-esteem is boosted. It would seem that his internal struggles have somewhat abated with his new role of being a permanent staff member rather than a casual employee. Here Casper may have found his niche with the present workplace-person fit. In a different vein, Coby accessed part-time employment as a green keeper as well as a position in retail after high school. He mentions this with excitement:

> Oh yeah, nana used to play golf when I was younger and I used to play with nana a bit. Also, I was going to the golf club for dinner and things like that. They didn't actually know me much, but they knew my grandparents, especially because my granddad does all the mechanic work for them for free (Coby, 424-428).

It would seem that Coby was comfortable at the golf course. He was familiar with the people there, having known them from a young age. He felt he was successful at the green keeper job for the following reasons:

> I felt like I did pretty well at that job. Probably helpful that there weren't tonnes of people there and I got on well with my boss. It was relatively simple.

> It's like you go and mow that lawn, you can go and mow that fairway or you need to do string trimming here. It was like I can do that (Coby, 157-163).

The green keeper job required Coby to work autonomously. His boss was familiar to him and he was provided with clear instructions. In this particular context, Coby appears confident that he has the skills to be a good green keeper. It is likely that with support from his employer and clear instructions Coby had the confidence to be successful in achieving set tasks. On the contrary, his experience in retail employment differed from his proficiency as a green keeper:

> I wasn't very social in the retail one… I feel like that was probably important. It was the opening of the store…There were positions available and I felt like probably the more social people tended to do better in that…I wasn't getting many hours (Coby, 133-140).

As opposed to working autonomously as a green keeper, the retail position required interaction with customers. However, difficulties with social interaction impacted Coby's skills at work. The importance of social interactions is highlighted here as a core component of being successful in retail employment. Coby speculates as to why he found both jobs different:

> You've got wait for customers or you've got to figure out how to put this particular thing here because you've got to do that and that. It's just a bit all up in the air. When you've got one task and it's fairly straightforward and you can just do it yourself, then it's like yeah that worked (Coby, 167-171).

When comparing both work situations, Coby's reference to "*up in the air*" indicates a lack of clarity in instructions as to what he was expected to do at the retail job. He recognises his difficulties interacting with customers, however, it would seem that in his sense of understanding, it was more the complexity of not knowing what was required of him that made him unsuccessful.

In a situation similar to Coby, Jade accessed part-time employment in retail immediately out of high school. She describes her interactions with her boss as follows:

> I needed very specific instructions. If they say mop the floor, how many people just mop the floor? I want to know what stuff you prefer, because generally in a lot of workplaces there might be a couple of different options of what they would use to clean the floor so I'd ask that… It just drove my boss nuts (Jade, 357-367).

Jade is emphatic about her need to be given clear instructions at work. This echoes with Coby's iteration above, and links to her earlier comments on the need for structure and routine. Changes in employment were also something reflected on by Mike. Mike has a certificate qualification in warehousing and accessed supported part-time employment in a warehouse for 5 weeks immediately after high school. Due to government cuts in funding supported work placement, Mike lost his job in warehousing and is since receiving support from a disability support service:

> So now I'm doing volunteering…Do the cardboard boxes, help pack the bales up. Do the electronic toys and cleaning (Mike, 38-44).

Through Mike's monotonous tone, it would seem that he finds the volunteering tasks menial. Given that Mike has a qualification, and has previously been in paid employment, it might be his expectation to access more paid work. However, the constraints of government funding for supported employment combined with Mike's inability to remain focused on tasks are likely to contribute to his prolonged engagement in volunteer activities. According to Romoser (2000), Mike is experiencing mal-employment, where he has the skill set in warehousing and has demonstrated the ability to work in paid employment, but works below his ability level. In this instance, Mike is dependent on disability funding and disability support services to access paid employment, and mentions that he would, "*like to use my warehousing skills*" (Mike, 52). Here Mike is cognisant of his ability level as he refers to his capability in his warehousing skills.

Family Advocacy in Seeking Employment

Support from family emerged as a key part of conversation will all the young adults interviewed. Coby and Jade mentioned their dependency on families in advocating for employment through extended family networks. Additionally, for Coby and Casper, family played a key role in facilitating social support and friendship. Coby's grandparents played an important part in his life, and always have since he was young:

> Well I used to see them every Friday when I was living with mum and dad…I suppose the thing is I felt like they were a bit more understanding, especially when I was younger… because at least they treated me in a way that I felt was better (Coby, 408-414).

Here Coby acknowledges the close relationship he has with his grandparents. His innuendo in, "*I felt I was better*" seems to reveal a disjointed relationship with his immediate family at home. As he later reveals:

> As I said, it's not a super supportive relationship. They do help me with financial things and mum doing washing and all the cooking and stuff, but it's not one of those emotional support kind of things, it's not particularly understanding (Coby, 304-307).

It would appear therefore that the immediate family is supportive in meeting Coby's daily needs, but he shares an emotional bond with his grandparents. Indeed, it was the grandparents extended social network with the golf club that provided a link for Coby to access part-time employment:

> The green keeper one was because my granddad is quite involved in the local golf club and also nana to an extent. They know my family, so that was a bit easier because they know that I'm not some random person (Coby, 112-117).

It is likely that the grandparent's relationships with people at the golf club provided an opening for Coby to get the job as a green keeper. In a similar vein, Jade acknowledges her sister's help in getting her first job. She also alludes to the support she has from her sister in general:

> We might not have much of a personal relationship but we still care about each other very much and we still try to help each other out in a practical sense. We don't ask each other how we are but we do practical things for each other. Yeah, she helped me get that job, which was pretty cool (Jade, 343-347)

On the one hand, Jade’s reflections here position her sister in a supportive sibling role in finding employment for her. Yet on the other hand, her tone indicates somewhat limited communication with her sister. Specifically, her reference to, “*we don’t ask each other how we are”* would indicate a detachment in the social niceties and flexible small talk of day-to-day communication. However, her sister was supportive in advocating for Jade to get a job at her workplace. Similarly, Casper recalls his family support immediately out of high school, especially from his mother:

> Yeah, they were pretty supportive towards me when I was transitioning out of high school and that. Like helping me look for a psychologist and that. But from memory I remember them being fairly supportive. I remember…it was my mother who helped organise the job provider after high school (Casper, 72-78).

Casper’s mother identified a priority in seeking support from a psychologist to assist him with the transition out of high school. She was proactive in accessing disability employment services for Casper to gain employment after high school. Her advocacy would appear to be an underlying driving force in all of Casper’s subsequent interactions with employment service providers of which he has had many. On a different note, Coby reflects on the social activities he shares with his family, especially time spent with his mother:

> I would go to the movies with her and that kind of thing. So pretty much all the recreation kind of stuff I do with my parents. We'd sometimes go to a family friend on the Gold Coast, see them on the Gold Coast, or go to a shopping centre (Coby, 335-340).

It is likely that Coby’s family observed his loneliness and isolation and might well be that Coby’s mum is actively engaging with him by going to the movies as a way to encourage him to interact with extended family.

Summary

In summary, participants appeared disappointed at the menial types of employment accessible to them immediately after high school. However, they recognised that their individual personalities might have contributed to negative employer perceptions of them as different. Jade was emphatic of her need for structure, routine, and clarity which "*drove my boss nuts.*" Coby thought he was unsuccessful in retail because he "*wasn't very social*", and Casper lost hours of work and received reduced pay because "*they treated me different.*" In Mike's experience, he is currently unemployed because "*the government cut the funding.*" However, both Casper and Coby reflected on their increased self-confidence at being successful later in the transition process, in accessing employment that matched their skill set and abilities. Coby gained confidence in working at the golf course that was a familiar environment and understood clear instructions that were given to him. Indeed, the increase in work hours gave Casper a sense of purpose in being part of a team and working at the level of his peers.

Theme 4: Functional Independence

The shift into independent living, coping with the demands of daily organisation, and living skills pose challenges for all young adults as they transition to adulthood. However, for young adults on the autism spectrum, functional independence is particularly challenging as these individuals face added difficulty which impact daily living activities such as time management, financial independence and driving (McCollum, LaVesser, & Berg, 2015). Of the participants interviewed, Mike lives with his family whilst Jade and Coby have lived in shared accommodation for the last 2 months. Casper has previously lived in shared accommodation but currently lives with his family.

Family Support

It is known that individuals with disability have special needs that require attention and greater effort from their families than neurotypical peers (Higgins et al., 2005). Additionally, research has demonstrated that the majority of adults with high intellectual ability remain dependent on their families (Billstedt et al., 2005; Howlin et al., 2004; Migliore et al., 2012). To some extent, the young adults interviewed were dependent on their families in varying degrees to meet different needs. For example, it would appear that whilst Coby is living in shared accommodation, his parents provide some informal support:

> I suppose a lot of the stuff mum and dad still provide, so I'm still on my phone plan and insurance for cars and stuff. They help me out. They do help me with financial things and mum doing washing and all the cooking and stuff (Coby, 266-306).

Here Coby appears to be dependent on his family for both financial support and daily chores such as cooking meals and the laundry. It is unclear as to whether Coby has received life skill training in independent living skills either at school or at home.

Challenges in moving out of the family home are highlighted by Jade. Although she prides herself in being organised, she expresses her surprise:

> It was a bit of a shock when I moved out. I'm comfortable with all household tasks. I'm well trained in that so I can do everything and I can cook and clean and laundry and stuff. I just really underestimated the amount of time required to do these things (Jade, 389-391).

However, she feels comfortable in managing her budget:

> It's basically the case that - the money that I do earn and stuff I put it in the account for all my bills and stuff so it just kind of happens automatically, automatic transactions for all my bills (Jade, 462-465).

Jade’s independence is articulated in her household organisation skills that she acknowledges being taught. It might be that Jade learned daily living skills from her family. However, her reference to length of time required in household chores hints to a possible juggle of time management.

Casper has had several experiences in shared accommodation with friends. However, at present he chooses to live with his family:

> I live with my family at the moment. I save money. So, I'm earning my own money away from welfare at the moment so that's good. But at the moment I'm currently paying off my car so I'm trying to keep an eye on my money. I still get the disability concession card from a [Welfare Agency] (Casper, 196-213).

At his late stage of the transition process at the age of 25, Casper manages his budget so that he can pay his car loan, has chosen to live in the family home to save his money, but still accesses some disability support. Mike, on the other hand when asked about his finances and budget responds with, "*I can't remember*" (Mike, 134). Mike receives the disability support pension, lives at home, and spends most of his time watching television:

> I like to watch some crime shows like NCIS, CSI, Midsomer Murders, Mysteries, Sherlock and Bones. [What do you do on the weekends?] Not a lot (Mike, 126-145).

It is likely that Mike is dependent on his parents for financial organisation of his disability pension, and daily support as he mentions, "*my dad drops me off and picks me up*" (Mike, 101) from his place of volunteer work.

Both Casper and Mike live with their family however both have different perspectives of their transition to adulthood. Mike aged 18, is dependent on his parents and disability support services, whilst Casper aged 25, has a car, is in paid employment, yet chooses to stay with family to save money. It would appear that within the age continuum of 18 to 25, transition experiences in functional independence and employment access differ in the young adults interviewed from those who have just completed high school (e.g., Mike) to those who have had a range of life experiences (e.g., Casper). It is unclear however, as to whether transition support strategies at high school, family support, or indeed whether age of diagnosis and understanding of ASD challenges impact how participants across the age group understand the transition experience.

Self-advocacy and Success

Participants' experience of the transition to life after high school varied as did their self-advocacy. Coby continued to grapple with difficulties in socialising and adjusting to new situations, whilst Mike appeared uncertain at the possibility of accessing meaningful daily activities. Jade, Casper, and Coby were proactive in exploring alternate avenues to facilitate their shift into adulthood in a positive way. For Jade, the initial experience of moving from a structured school routine to university was overwhelming:

> I think the transition from school to university was an absolute shock because you go from the structure of school then after school it's like everything's gone. There's no structure. There's no routine. There's no due dates or anything like that. You've just got to make it up yourself (Jade, 39-46).

Here Jade reveals a sense of angst, as she attempts to cope with the newness of the situation. Jade echoes her need for daily structure and routine to feel productive as mentioned earlier in Theme 1, *Understanding their ASD*. However, Jade was proactive and chose to disclose her ASD and specific learning needs to the student support services at her university. Consequently, she currently receives academic support through the university student services:

> Things like the exam adjustments are very helpful because I've got hypersensitive hearing. Basically, when I'm in a class exam I can hear someone's pencil from the other side of the room. Basically on the plan is that I can have my exam in a room by myself so I'm not hearing everybody else, which is cool (Jade, 260-321).

Jade feels comfortable having her specific learning needs documented in a learning support plan that all her lecturers have access to. This allows her the flexibility to access a learning environment conducive to her specific needs.

Coby's transition pathway after high school consisted of a series of choices ranging from a gap year "*of doing nothing*" (Coby, 80), to doing odd jobs, then studying as an external student. The theme of loneliness and isolation re-surfaces as Coby starts university:

> When I was starting to come on campus, I didn't really know anybody obviously and I wasn't really that great at meeting people either. So, in the end I tend to use things like doing extracurricular activities to try and meet people because one of the reasons I'm going to be coming on campus is to meet people (Coby, 186-190).

Here Coby is aware of his isolation in being at home and studying as an external student, and is proactive in accessing extracurricular activities at university to increase his social participation. However, he shares a similar experience to Jade when he firsts encounters the university environment:

> I went until the census date, so four weeks, and then quit. That one was like really fully intimidating because like you're going into these massive classes and you don't really know who to talk to or you don't know anyone. It was just over the top for me (Coby, 82-86).

Here Coby reveals an overwhelming sense of fear of the unknown. In his experience, the classes were unstructured and different to his high school experience and he is astounded. It might be the case that Coby may have benefitted if the university had a transition program for students requiring additional academic and social support (Adreon & Durocher, 2007; Barnhill, 2016; VanBergeik et al., 2008). It is likely that Coby's inability to cope with the new environment, rather than academic difficulty, was a contributing factor in his decision to leave university.

On the contrary, as he got older, Casper was proactive in addressing the low self-esteem and social anxiety that he experienced in high school:

> Well at the moment I run a Facebook social group for people on the autism spectrum. We meet Saturday fortnightly and we have meetings at the Brisbane Library and sometimes I'll organise events such as like barbecues or movie outings (Casper, 90-97).

It is possible, that as Casper is now older, he has developed strategies to cope with different traits of his ASD, one of which is making friends through his online Facebook social group for young adults on the autism spectrum. Casper's response is both proactive and self-advocating in establishing an online ASD community social group to extend his social network in an environment that he is comfortable with.

In a different vein, having just completed high school, Mike is dependent on disability services:

> I do darts Mondays, Tuesdays in respite. Thursday afternoons I'm doing computer group and Fridays, still talking about it, respite (Mike, 58-60).

Here Mike's tone is dependent on disability support to access ongoing social interaction through respite activities. It is likely that as Mike has just completed high school, is receiving the disability pension, and has support from disability services, he is in a comfort zone.

Summary

In summary, Jade and Coby found the transition to university and moving out of home overwhelming. According to a recent study by Henninger and Taylor (2014) moving out of home, skills required for daily functioning, and pursuing academic pursuits were rated as key elements for a successful transition to adulthood in adolescents on the autism spectrum. In the present study, family advocacy was highlighted in facilitating access to employment, providing accommodation, and financial support. Some participants managed challenges through proactive choices. For example, Jade chose to disclose her ASD to access academic support at university that resulted in a learning support plan, that accommodated her specific learning requirements. Casper was proactive in forming an online ASD Facebook social group to increase his friendship and social activity. However, Mike remained dependent on respite with a disability support service to access volunteer activities and social activities on a regular basis.

Discussion

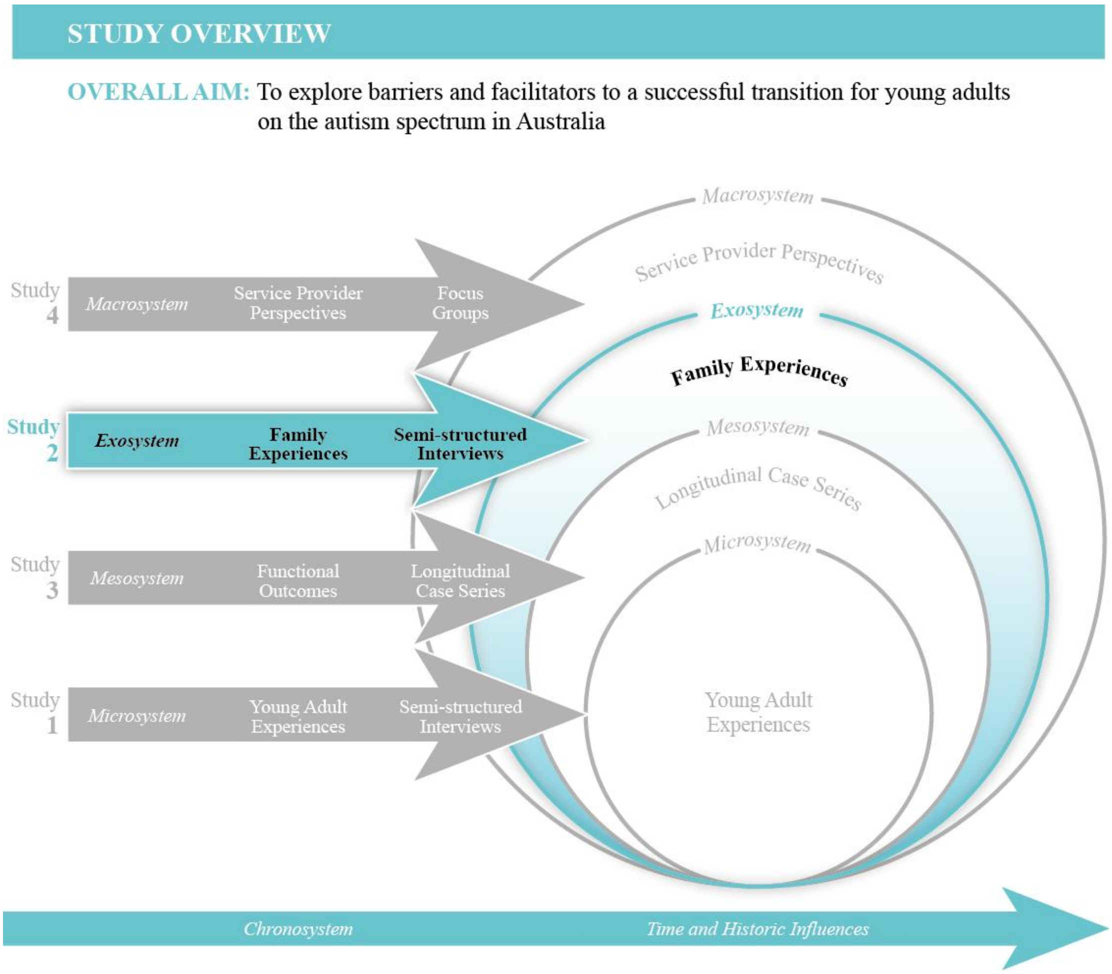
The purpose of this chapter was to address the research question: *What are the experiences of young adults on the autism spectrum as they transition to adulthood?* This study is notable for its focus on individual perspectives by listening to the voices of four young adults on the autism spectrum to learn firsthand, and to capture the complexities and challenges of their transition experiences. IPA (Smith et al., 2009) was chosen as the methodology as it allowed young adults to reflect on and make sense of their lived transition experiences through in-depth semi-structured interviews. Through the lens of Bronfenbrenner's Ecological Model (1994) young adult interactions within the microsystem of transition experiences in independent living, friendships, post-secondary education, and employment were also explored. The findings from the present Study 1, and the next study, Study 2, will be used to inform the development of the quantitative pilot longitudinal case series in Study 3, which will be reported in Chapter 5.

Study 1 identified four main themes within the transition process, each with two subthemes. The four main themes were, *Embracing ASD Differences, Social Interaction, Employment,* and *Functional Independence.* Within the main theme, *Embracing ASD Differences,* there were two specific subthemes, informed by specific lived experiences relevant to participants' life-world. Within the first subtheme; *Understanding their ASD Differences*, across the age continuum of 18 to 25, this subtheme provides a basis for some comparison of life experiences and individual responses over time; for example, from Mike (aged 18) to Casper (aged 25). On the one hand, for participants at the early stage of the transition experience, there appeared to be a disconnection between embracing ASD differences and a sense of self-advocacy. On the other hand, it appeared that for participants at the later stage of the transition experience, proactive behaviour in disability disclosure, seeking study assistance, forming a Facebook ASD community social group, and actively seeking membership of on-campus student councils, embodied a sense of self-determination and ownership of identity in progressing future successes. Indeed, the short responses from Mike in punctuated phrases was an enactment of what Kanne et al. (2011, p. 1008) refer to as, a typical "*autism profile*" in limited interaction and communication with the researcher who was unfamiliar to him. Further, Mike's choice of a telephone interview rather than face-to-face interview affirms his possible discomfort in social interactions. Whilst this is not to be perceived as a study limitation, it does however exemplify the subtle nuances of this progressive research in speaking *with* individuals on the autism spectrum as opposed to speaking *for* them.

Summary

This chapter presented the analysis and findings from semi-structured interviews with young adults on the autism spectrum, conducted in Study 1. As discussed previously, parents are often the primary caregivers for their young adult children on the autism spectrum, and play an import role in the transition process. Therefore, asking parents of their experiences during the transition to adulthood provides a holistic perspective of wants and needs within an ecological systems framework. The next chapter, Chapter 4, will present the analysis and findings from semi-structured interviews with parents of young adults on the autism spectrum, conducted in Study 2.

Chapter 4 – Study 2: Voices of Parents



STUDY OVERVIEW

OVERALL AIM: To explore barriers and facilitators to a successful transition for young adults on the autism spectrum in Australia

Figure 4.1. Flowchart summarising Study 2, family experiences within the exosystem.

Background

Over the last two decades, children diagnosed on the autism spectrum received access to early interventions and special education services. The expectation therefore, is that findings in current research would demonstrate improved outcomes with this population as they leave school and move into adulthood (Taylor & Mailick, 2014). However, follow up studies over the last decade indicate that the number of adults on the autism spectrum living independently or semi-independently and rated as having a good outcome and quality of life (QOL) is poor (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Eaves & Ho, 2009; Farley et al., 2009). Many remain dependent on their parents as primary caregivers, lead isolated lives, and parents are left with the worry of who will look after their children when they are no longer able to care for them (Smith et al., 2012). This chapter will present the method, analysis, and findings of semi-structured interviews with parents of young adults on the autism spectrum, followed by a general discussion of the study findings. The present study strengths and limitations, implications of findings, and future research directions will be discussed in the general discussion in Chapter 7.

There is a growing body of evidence that indicates caring for an individual with a disability has a negative impact on family and family functioning (Boehm, Carter, & Taylor, 2015; Browne, & Bramston, 1998). More specifically, mothers of children on the autism spectrum are at significant risk of increased stress, depression, physical, and emotional problems when compared to mothers of typically developing adolescents (Howlin & Moss, 2012; Seltzer et al., 2010; Smith, Seltzer, & Greenberg, 2012). As mothers' cope with the physical and emotional demands, disruptive and compulsive behaviours associated with ASD, they face feelings of inadequacy, failure, guilt, and frustration (Higgins et al., 2005). The high heritability of ASD means that many families may have two or more siblings on the autism spectrum, with some parents themselves displaying ASD differences and difficulties (Howlin & Moss, 2012). Such factors may preclude a typical family life as mothers are faced with low self-esteem, and low self-confidence impacting their psychosocial wellbeing (Higgins et al., 2005). As discussed in Chapter 1, according to a recent review by Synergies Economic Consulting (2011) the most significant impact was found in reduced income due to low employment rates for both parents and individuals on the autism spectrum and a high dependency by individuals on the autism spectrum on families. In light of these concerns it becomes increasingly important to understand how families are impacted by the transition to adulthood.

On a global level, much of the extant research in ASD has focused on the diagnosis, treatment, and psychosocial interventions for children on the autism spectrum (Howlin & Moss, 2012; Tobin et al., 2014). Whilst there is an emerging body of Australian literature on adults on the autism spectrum, the vast amount of ASD research focuses on parents with young children, with limited information addressing how families of young adults on the autism spectrum experience the transition to adulthood (Beamish et al., 2012; Higgins et al., 2005). These factors combined highlight a growing need to describe parent experiences as their young adult children on the autism spectrum transition to adulthood. Such parental insights will inform the development of appropriate interventions and services for both young adults on the autism spectrum and their families.

Significance of the Present Study. The present study focuses on families and their experiences as their young adult child on the autism spectrum transitions to adulthood. The purpose of this phenomenological research was to explore parent perspectives of their young adult child’s transition journey to independent living, friendships, post-secondary education, employment, and to identify both family and individual needs and supports during the transition period. The research question guiding this exploratory study was: *What are the experiences of parents of young adults on the autism spectrum during the transition to adulthood?*

Method

Qualitative research using semi-structured interviews was chosen to allow for an in-depth investigation and broader understanding of the lived transition experience, thus identifying specific factors relevant to families. As discussed in Chapter 1, Interpretative Phenomenological Analysis (IPA) was used to analyse the interview data (Smith et al., 2009). The use of the first person is indicative of my transparency in a coherent presentation of the systematic IPA methodology that I employed throughout my research journey (Yardley, 2000).

Recruitment

Ethics approval was granted from the University of Southern Queensland's Human Research Ethics Committee prior to recruitment (USQ: No. H15REA227). Participants were recruited through ASD support organisations and the researcher's networks. The Participant Information Sheet (Appendix D) was e-mailed to Autism Spectrum Australia, Autism CRC, Asperger's Australia, and advertised on parent and community Facebook groups. Participants who were interested contacted the researcher and were then e-mailed a consent form. Inclusion criteria were that participants were parents of young adult children between the ages of 18 to 25 with a medical diagnosis of ASD, currently experiencing transition, and lived in Australia.

Participants

Participants who responded to the study advertisement were all mothers of young adults with an ASD aged 18 to 25 living in Australia. Mothers in the present study were not necessarily mothers of young adults in Study 1. Guided by Smith et al.'s (2009) recommendations on sample size for a Doctoral thesis, five parent participants were interviewed. Whilst maintaining a commitment to the idiographic nature of IPA, having five participants allowed for a rich depth of analysis of similarities and differences between individual experiences (Willig, 2013). Mary and Carol have two young adult children on the autism spectrum and both were interviewed twice, that is, one interview for each child, thus a total of seven interviews. Participants' young adult children ranged in daily occupation status from volunteering to paid employment, to attending a Technical and Further Education (TAFE) college or attending university. Participants were provided with the opportunity to select a pseudonym and were informed that all identifying information would be changed. Table 4.1 summarises participants' key demographics.

Table 4.1

Study 2 Participants' Demographics

Mother	Occupation	Young Adult	Age at diagnosis	Gender	Age	Occupation
Lua	Teacher	Bob	11 years	Male	24	University Student
Mary	Teacher	Tim	12 years	Male	24	College Student
Mary	Teacher	Vanessa	14 years	Female	18	University Student
Sue	Shift Worker	Matt	9 years	Male	18	Volunteer work
Carol	House Duties	Adam	7 years	Male	20	Paid employment
Carol	House Duties	Addie	8 years	Female	18	University Student
Meg	Home Duties	Kay	20 years	Female	22	University Student

Interview Procedure

Informed consent was gained prior to the interview (Appendix E). Semi-structured interviews were conducted to gather personal appraisal of experiences to independent living, post-secondary education, employment, friendships and overall life satisfaction during the transition to adulthood (Smith et. al., 2009). Participants were informed that interviews would be recorded and all information would be anonymously reported. Participants were provided a choice of telephone-interview, online conferencing, written response, or face-to face interview. These were considered appropriate methodological options due to their flexibility in terms of geographical location and time imposition. Previous research reports these methods as being less intrusive to families and individuals on the autism spectrum (Eaves & Ho, 2008). Two mothers were interviewed face-to-face and three mothers were interviewed by telephone due to geographical location. Participants were provided with questions prior to the interviews to facilitate comfortable communication and ease any possible anxiety (Appendix F). Questions explored participants' experiences with support at school, family support, disability support services, post-secondary education, social interaction and the impact of ASD on the transition process. My interview technique was based on empathic understanding and semi-structured interviews were used to facilitate rapport with participants (Smith et al., 2009). For example, the opening question, "*Can you tell me a little bit about your family background*?" was used as an icebreaker to build rapport with participants. Interview questions were largely open ended to elicit in-depth meanings, for example:

- Can you tell me a little bit about your child with ASD?
- What are some of the challenges that you and your child faced whilst your child was at school?
- What are your experiences with disability support services?
- Does your child's ASD impact how they interact on a daily basis?

I developed a flexible interview schedule with my supervisors and open-ended questions were incorporated as a prompt if further details were required (Yardley, 2008). I engaged in participant checks during the interview to clarify my understanding of the issue (Kvale, 1996). Participants were interviewed individually for 45-60 minutes each, in mutually agreed locations and interviews were recorded on a Zoom H2 Handy Recorder. Participants were informed that transcriptions of the interview would be made available to ensure transparency, credibility, trustworthiness, and participant validation (Willig, 2013).

Data Trustworthiness

Parallel criteria of trustworthiness in credibility, transferability, and confirmability were employed in this study (Lincoln & Guba, 2000). Authenticity and transferability in the presentation of original interview quotes and thick descriptions ensured qualitative rigour (Cohen et al., 2000; Lincoln & Guba, 1986). Credibility of findings was demonstrated by lengthy and intensive engagement with participants during interviews that lasted between 45 to 60 minutes. At the end of each interview, member checks were conducted with each participant to verify the information provided in response to questions asked during the interview (Creswell & Miller, 2000). Of the five participants interviewed, one participant engaged in a second round of member checking of interview transcript with no changes suggested. Finally, to ensure confirmability of the findings, IPA qualitative methodology, associated hermeneutic phenomenological contexts and researcher reflexivity were discussed with explicit detail in Chapter 1 to support the analytic approaches chosen in this study (Lincoln & Guba, 1986).

Data Analysis

Interviews were transcribed verbatim implementing the recommendations for transcription for IPA by Langdridge (2007). Transcripts were secured in a locked filing cupboard during all stages of analysis. The analysis closely followed the four-stage process described by Smith et al. (2009). During the first stage, I engaged with the data through listening to the recordings and reading and re-reading the transcripts to become familiar with participants’ responses (Willig, 2013). Once immersed within the data I began annotating my initial exploratory comments in the right margin based on specific ways participants spoke, thought and understood issues associated with their role in the transition process. I reflected on my initial analysis with my supervisors who reviewed and commented on my initial codes. I then re-read the transcripts with a focus on the linguistic tools and metaphor used to colour participants' voices as they spoke of important things that made up their lived transition experience (Willig, 2013). For example, Lua' reference to "*my blood pressure going up through the roof*" (Lua, 649) hints at a deeper innuendo of difficult interactions with her son Bob, leading to difficulties with her health.

During the second stage, whilst staying close to participants' personal perspectives, I re-read individual transcripts to discover emergent patterns that I then noted in the left margin (Smith et al., 2009). I approached each transcript as an individual case and was sensitive to specific nuances, differences and commonalities that brought participants experiences to life (Elliott et al., 1999). For example, throughout the interview with Mary, a recurrent theme of financial hardships was interwoven in her narrative. I looked for echoes of ideas and areas of tension as my analytic attention moved from individual cases to the shared experience across cases (Eatough & Smith, 2008). For example, in Carol's responses, her comments on expenses associated with her children were closely linked to Mary's experience of financial hardship.

During the third stage the themes were further explored in order to make connections between them. For example, with Mary, Carol, and Lua, a link across cases resulted in a theme of *Family Challenges*. As emergent themes were identified I grouped them into higher order categories, and superordinate themes were determined based on the frequency that they occurred across cases (Willig, 2013). For example, all mothers pondered on their children being independent in important areas of adult functioning such as independent living. Thus, the importance in presenting their shared concerns of how ASD impacted their life-world was captured in the superordinate theme of *Future Success*.

During this third stage my supervisors again reviewed and edited themes to ensure they were grounded and well represented in the interview transcripts. My supervisors and I engaged in regular dialogue about the coded data and what this might mean for the participants within the transition context. After analysis of individual transcripts, patterns were coded across transcripts. In the fourth stage, IPA analysis of the data resulted in an overarching of four superordinate themes relevant to parents lived experiences of their young adult's transition to adulthood.

Findings

The four themes resulting from IPA analysis were *Family Challenges, Functional Independence, Support Experiences,* and *Family Advocacy*. Although these themes are presented distinctly, they are interrelated in forming the experiential understanding of participants. The four superordinate themes and their components are presented in Table 4.2 below.

Table 4.2

Themes Emerging from an Interpretative Phenomenological Analysis of Interviews with Mothers of Young Adults on the Autism Spectrum

Theme	Theme Title
Theme 1	Family Challenges • Sibling Stories • ASD and External Impacts
Theme 2	Functional independence • Current State • Future Perspectives
Theme 3	Support Experiences • School Support • Post-school Support
Theme 4	Family Advocacy • Mother's Persistence • Supported Social Interaction

Theme 1: Family Challenges

All mothers reflected on the differences they observed in their young adult children on the autism spectrum when compared to siblings. Some mothers spoke about challenges in family relationships, interactions with siblings, and difficulties with their young adult child on the autism spectrum not being able to fit in. Other mothers spoke about heartfelt personal impacts in loss of support funding, sacrifices in daily amenities, and financial hardships. A common thread interwoven throughout their stories was the significance of the family functioning together as a foundational and cohesive support system.

Sibling Stories

Mary has two young adult children both with an ASD. Her son Tim has a naturally loud personality, and Mary mentioned several episodes where Tim would dominate conversations at home, and overshadow and taunt his younger sister Vanessa:

> I thought that her language difficulties were perhaps because my son, her older brother, always did all the talking and held the floor and she didn’t get to practice her talking as much (Mary, 8-11).

Here Mary reflects on Vanessa’s initial language difficulties and diagnosis of ASD. She speculates that Vanessa’s diagnosis may have been prolonged due to Tim’s dominating conversations. Consequently, according to Mary, Vanessa is more conservative. Due to Tim’s overbearing behaviour, Mary dedicates one-on-one time on a daily basis to spend with Vanessa. In a similar vein, Lua explains the love-hate relationship between Bob and his younger sibling:

> He used to be very cruel to his younger brother. Just teased him, knew the buttons to push. Boy have they been violent with each other. I've had to get in the middle of them. Bob thinks he's been funny, and Bob thinks he's being friendly, but Bob's being a bully (Lua, 513-524).

In both Mary and Lua’s lived experiences, their children demonstrate aggressive behaviour towards their siblings. Indeed, living with an individual on the autism spectrum can be a source of constant stress for parents and impacts family relationships and coping mechanisms (Howlin & Moss, 2012). In response to the situation above, both mothers intervened to support or protect the younger sibling. Meg, however, reflects on her daughter Kay’s discomfort around siblings, especially at family gatherings:

> She just thinks she has nothing at all in common with them…She just doesn't feel she fits in. She does attend family dinners and special occasions, but she has commented that she feels she doesn't fit in (Meg, 196-201).

There seems to be an underlying tension in Kay’s behaviour. It might be the case that whilst Kay attends family functions because it is expected of her, she is uncomfortable interacting at a social level with her siblings. Perhaps Kay senses this conflict within herself as she has voiced her difficulty with not being able to “*fit in*” to Meg.

ASD and External Impacts

All mothers spoke about the adjustments to family life, living with a child on the autism spectrum. Some spoke about the broader impacts on ASD on finances and juggling day-to-day activities. In Lua’s family, it would seem that her family functions as a supportive unit with a primary focus on Bob:

> We know what he's like, and we know how not to stress him out…He can hold it together for a short time but when it gets too much, that's it, he can't handle it. To be honest home is where he lets it go (Lua, 329-333).

Lua’s family is aware of triggers that stress Bob, as they appear to be supportive of him when he is overwhelmed and experiences a meltdown:

> The family dynamic is set up around the fact that both the boys have autism and both the boys need this. I've always looked at it, we are a large family and we're a very supportive family. So I prefer not to use things like respite myself. So, we've always played it that way (Lua, 683-689).

It does seem, however, that the family’s daily functioning is centred on Lua’s sons on the autism spectrum. Whilst Lua alludes to a shared family responsibility in caregiving for Bob, it might be the case that tension in the household is constant. As she mentions below:

> I'm trying to pull back a bit. I'm trying not to be - because he has to be independent. That's always been my thing…it frustrates me having to nag him. I mean I end up with my blood pressure going up through the roof (Lua, 646-649).

Although Lua’s family is supportive, it seems as though the bulk of responsibility in caregiving for Bob is on her. On the one hand, she wants to support Bob to be independent as he moves into adulthood, yet on the other hand her constant mothering is impacting her health. Her reference to her escalating levels of emotions would indicate her distress at constantly managing Bob.

Within a broader context, some mothers mentioned the lack of resources and the impact this has on families. As a single parent, Mary appears dismayed as she refers to her shock at a lack of disability financial support for her son Tim:

> No, we don’t access any funding. This was a shock to me when he finished school. Because I am working full-time and he is living with me, we're not able to access anything. So as soon as the children turn 18, then the small amount of child family payment is gone (Mary, 227-237).

It would seem that whilst Tim accessed support at the school level, he is no longer entitled to support within the adult system. In a similar vein, Carol shares Mary’s angst and speaks about her experience accessing support for Addie:

> She had all the documentation and heaps and heaps of specialists, they still declined her support after you're sixteen. I then went to her paediatrician to do more paperwork. They still disagreed with it. She needs this help even if it's just the carer's allowance card. I think that their reasoning is once you're 16 somehow mysteriously autism disappears and anxiety and depression disappears (Carol, 246-249).

Meg echoes both Mary’s and Carol’s circumstances and mentions this about Kay:

> We didn’t get anything for her. So, it made it hard for her because she was entitled to stuff she couldn’t get. So, we used to have just make-up the short fall for her. Actually, mum lives with us, and mum used to give her money every fortnight out of her pension. She had a car, so we used to have to give her money for fuel, rego, insurance, all the basic stuff (Meg, 250-255).

Here it appears that the extended family play a key role in contributing to supporting Kay’s financial needs as well as alleviating some of the financial burden of her parents. Through their lived experiences, Mary, Carol, and Kay persevered to access support for their young adult children by following all systemic protocol. However, it would seem that the adult support system was oblivious of their specific needs.

For Mary however, as she is a sole parent, the impact of a loss of financial support for her children can be seen in her life choices and the financial implications for her family:

> We started saving last year by cutting out different foods. Things that we would have bought before, we no longer buy. We'll eat more rice or more pasta or more bread and less meat. Which has been very difficult for my son because he can't understand why he can't live like he did before (Mary, 174-178).

In addition, it would seem as though the financial strain has a ripple effect on Mary’s social interaction at work, as well as access to facilities such as the Internet:

> We kept the Internet. For me, as an adult, I often cannot participate in the social activities at work. Because I have to make the decision…sometimes the places they go to are $100, will I do that, or will I look at buying five kilograms of meat. I always choose my family first. So, it impacts me socially (Mary, 183-190).

Furthermore, Mary envisions a daunting year ahead financially as she faces medical expenses:

> It will get harder this year as it starts to impact. With the health insurance and things like that, I have to look at very seriously whether I can continue being in the private system (Mary, 178-180).

In all of Mary's iterations above there is an emergent pattern of financial despair impacting both her and her family's quality of life. Carol echoed Mary's concerns and explains the time she has dedicated and the financial impact in securing a position in a mainstream school for her children on the autism spectrum:

> We had spent a lot of money and a lot of time getting the kids to be able to go to mainstream school, giving them private speech therapy, getting their Irlen Syndrome lenses every year and all sorts of stuff to maintain them to be able to be at mainstream school (Carol, 446-450).

There is an underlying innuendo here that a different school setting may have been an alternative option for Carol's children Adam and Addie. Carol has explored several medical interventions to support her children, and is adamant throughout our interview as she highlights her children's academic capabilities. In Carol's experience, she has gone to the extent of seeking private support services at her own financial expense, almost as a guarantee to ensure her children gained access to mainstream schooling.

Summary

Family challenges were something that mothers referred to, in interactions with siblings, the social-emotional, and financial impact on family functioning and coping strategies. Indeed, according to Higgins et al. (2005) aggressive behaviour in older children on the autism spectrum impacts sibling and family relationships. As can be seen with Lua, her constant wrestling with Bob's aggression and dependency impacts her health. Of note is the financial strain on Mary as she navigates managing a household as a sole parent without disability support for both Tim and Vanessa. Her life experience is a lived reality down to the choices of the basic necessities of food or the Internet. Similarly, Carol is an active advocate pursuing all avenues of private counselling and support at her personal financial expense to ensure her children are positioned with peers within a mainstream school.

Theme 2: Functional Independence

All mothers expressed concerns about how their children would live and function independently in the future. Some mothers spoke about life-skills that they taught their children to facilitate independent living. At the same time, mothers noted their own anxiety as they observed the challenges their children faced, whilst transitioning to living away from home. Indeed, accessing paid employment, managing budgets, coping with daily household chores, and mobility in gaining a driver's license are role markers of adult independent living (Howlin et al., 2004; Lawer et al., 2009; Taylor & Mailick, 2014). In addition, mothers' future hopes for their children revolved around partners and relationships and in generally being safe.

Current Situation

Carol perseveres in teaching both Adam and Addie budgeting skills, teaching Adam how to drive, practicing cooking skills, making up shopping lists, and how to use public transportation. Through all of her persistence and years of explicitly teaching her children life skills, Carol expresses this view of Addie attending university and living away from home:

> It's a family and she's renting a room. She can't handle people so she spends more of her time in her bedroom there. She is finding it challenging. So, her diet is now consisted of packet soups and stuff like that because she just can't handle it, but I think in one way she's thrown into the deep end…it could be good because she has to try and deal with people (Carol, 266-275).

Whilst Addie would appear to be a high achiever, attending university and living away from home, functioning independently is still a challenge for her. Initially, Carol worries about Addie coping with living away from home. However, on reflection, she wonders whether Addie being faced with new situations and challenges might force her to talk to people that she lives with. Here it seems as though Carol views Addie's move out of home as an opportunity for her to interact with other people and develop her communication skills. Conversely, Carol’s son Adam has recently moved out of home into shared accommodation. Her observation is:

> It's a struggle because Adam can't really cook… He realised that I budget things and I've told him he's got to try and budget. I think he didn't really fully understand the consequences of moving out, like you do actually have to pay your bills, you do have to pay the rent, the power and all those utilities (Carol, 383-398).

Although Carol dedicated time in teaching Adam skills to live independently, her tone is anxious as she lists the basic household amenities that Adam is struggling to grasp. In a related vein, Lua talks about her son Bob’s dependency on her:

> So, we'd have to drive in to get his KFC. When I'm in town, mum, can you pick me up some jocks, or mum can you pick me up some shaving cream (Lua, 421-434).

Lua prepared Bob for his driving test and paid for driving lessons for him. She notes his attitude towards getting his driver’s licence:

> He said, I'm going for my driver's exam. I don't want to do it…it's a lot of money to fail it. He said, but I also don't want to pass it…I don't want to pass because I know once I pass it things will have to change (Lua, 302-311).

It would seem as though Bob is aware of his reliance on Lua. If he gets his driver’s licence, it would mean that he has to develop a sense of independence and take responsibility for shopping chores that Lua has previously done for him. It might be the case that Bob is fearful of a change to his routine dependency on Lua, hence his reluctance to pass the driver’s test. On the contrary, whilst Sue mentions that Matt has a qualification in warehousing, she recognises her son’s inattention and the impact this will have on him driving a forklift:

> He doesn't have a driver's license and doesn't intend to get one.
> That limits his ability to do things, because he has a Certificate III in Warehousing, for example he can't drive a forklift or anything. He has limited ability to multi-task. So, when you're driving a car you need to be able to multi-task because you need to be aware of lot of things all at the same time (Sue, 156-164).

Here, the concept of a driver’s licence is extended to Matt’s ability to drive a forklift. The underlying implication here for Sue is Matt’s limitation in accessing employment likely due to his inability to manoeuvre a forklift. It can be seen therefore, that in this instance a driver’s licence is important for Matt to gain employment. Sue’s thoughts resonate with Mary as she talks about her son Tim and the likelihood of driving:

> I would say with driving he could never - he gets very lost. He can stand at a street and he'll say, oh, which way do I have to walk. So, he relies a lot on the phone, on the maps, now. Thank goodness that they have them, also, he's very anxious too and very worried (Mary, 290-293).

Both Sue and Mary allude to safety concerns when talking about their young adult sons driving. Carol echoes these thoughts with Addie living away from home and travelling to university:

> The transportation is really challenging because she still doesn't know how to do that. She's just unsure about - she's got to catch a bus to go to a train station and from the train station catch another bus. So, she still hasn't grasped that part yet (Carol, 305-309).

Mary expresses further safety concerns that she has for Tim in his ability to navigate around the kitchen:

> He'd leave the water running or he'd leave the stove on. Like one day we left him for two hours and we came back and he said I've been having a barbecue. I said what you have been barbecuing? He said, oh, I was burning the weeds in the backyard (Mary, 259-272).

The responsibilities at this point of independence in young adulthood appear to be challenging for Tim. There are however, daily chores in adulthood that are traditionally not particularly demanding, such as turning the tap off. However, for Tim the hazard associated in experimenting with fire appear to be non-existent.

Mothers were sincere in acknowledging current struggles with their young adult children as they navigated adult roles and responsibilities. They spoke of challenges in daily living chores, transportation and employment, but were also quick to respond with support strategies and skill building activities that they initiated and implemented as they prepared their young adult children for a brighter future.

Future Perspectives

Parents pondered on the future of their young adult children on the autism spectrum with average to above average intellectual ability, as they faced the challenge of adulthood. For some mothers getting a driver’s licence was a marker of autonomy, whilst other mothers endured the reality of their young adult child’s constraints. For example, Sue’s tone appears to be frank, as she acknowledges Matt’s future dependency on the family:

> I don't see him moving out to be honest. I think that he will either be at home with us or in a group home situation. I don't think he'll be able to live independently (Sue, 167-169).

Mary echoes Sue’s statement above, and also acknowledges Tim’s inability to manage finances:

> No, he probably will never be able to live independently…we can now leave him on his own for a couple of hours and know that things will be safe, if he's asleep or he just spends time online on the computer…But he has no idea about money, finances, living day-to-day (Mary, 260-265).

Mary’s earlier thoughts on safety concerns for Tim are revisited in the quote above. In a reflective moment, Mary mentions Tim’s “*high intelligence*” (Mary, 63) and expresses her thoughts on what she would like for Tim as a parent:

> I'd like him to be independent. It was about five years ago that I realised…he maybe will never be independent and able to live and function by himself. He has high aspirations of what he wants to do and followed Steve Jobs until he died, and Bill Gates (Mary, 328-332).

Mary’s tone is melancholic as she shares her realisation of a gloomy future for Tim. On the one hand, she recognises Tim’s “*high intelligence”*, yet on the other hand, her concerns for Tim permeate all aspects of him functioning successfully in society. She struggles with this vision given that Tim is highly intelligent and a savvy computer technician. Here Mary's fears echo with Lua who also mentions this about Bob:

> He's highly intelligent. He's actually been tested. He's actually gifted, but he didn't like to be seen as different from anybody so he deliberately didn't do any work. He deliberately self-destructs his own pathway because if he's seen as smart then he's not like everybody else (Lua, 98-102).

Here, Bob's behaviour is focused more on fitting in with peers than in being successful at school. It would seem that being part of a peer group is more important to Bob than achieving at school.

Mary's thoughts for Vanessa's future are different. Whilst Mary is aware of the challenges in finding part-time employment in general for all young adults, she alludes to the ASD impact in social interaction and communication on Vanessa's ability to access part-time employment:

> The transition then, from studying to work, and now finding part-time work, finding part-time work is very, very difficult and it's very scarce. Because she hasn't worked in retail and she has the difficulty with the communication, then behind a counter serving somebody is very difficult for her (Mary, 193-197).

Here Mary details the current structure of some workplaces and the expectation of effective social interaction. Such expectations can limit the potential for individuals such as Vanessa. In contrast, other parents hold a promising view for the future. Sue is proud of Matt's qualification and she is hopeful that it will provide a pathway into employment for Matt:

> I would like him to be able to use his qualification because he has a Certificate III qualification in Warehousing, so I'd like him to be able to use that. Whether he's able to do it and use it is a different matter because he does require a bit of supervision. If you give him a task he's quite capable of doing it, but he doesn't have the ability to think outside the box or to think laterally (Sue, 95-100).

Here Sue alludes to ASD specific challenges in Matt's ability to function independently and productively in the workplace. However, she believes that with support and directed supervision Matt will be successful in the workplace.

In a different vein Lua returns to Bob’s dependency on her. She is persistent in attempting to develop a sense of independence in him:

> So, I'm always pushing him that he's got to do it. As I said, he sees me as the nag. I see it as me trying to be proactive and trying to set him up (Lua, 580-582).

She envisions Bob’s future as being dependent on a partner:

> Yeah, if he ever leaves home the independence will be very much based upon - he'll replace me with somebody that's willing to do that for him. Because that's his strategy, that's how he's got through everything he's had to do, is that he just falls back on me. I see that if he left home it would be to be moving in with somebody who would then take over my role (Lua, 571-622).

Lua appears nonchalant as she questions indeed, whether Bob will venture into independent living. Her matter-of-fact attitude alludes to a seemingly natural progression in Bob’s future in transferring his dependency on a partner taking on the role of caregiver rather than co-existing in a mutual relationship as a *proper* partner. On the contrary, Meg reflects on Kay’s independence and refers to her fixation in organisation:

> Well coat hangers for one, they can only be black. You don't mess with her things, she puts her things where she wants them and if you mess with them look out. But I just work around that, that's fine. I'd like to see her with a partner but they'd have to adjust to her little organisation. That might be a bit hard, but no I'd like to see her with somebody (Meg, 188-190).

Meg expresses a keen desire and has a positive expectation for Kay to have a partner in the future. Although Kay’s rigid organisation may appear unassuming, Meg is adamant of potential consequences if there is disruption to Kay’s structured organisation and orderliness. Whilst Meg has learnt to adjust her daily chores to accommodate Kay’s fixated habits, this may not be so easy for a future partner.

Summary

All mothers referred to issues of independence in daily living activities, budgeting, cooking and transportation. Some mothers expressed concerns around relationships with future partners. A recurrent theme with Mary was of safety concerns for Tim being left alone at home. Indeed, there is an underlying tension throughout the mother's narrative. On the one hand, they acknowledged limitations in their young adults' ability to function independently in society. On the other hand, for Lua, her constant mothering appeared to be a crutch in supporting Bob's independence. To some degree, all mothers acknowledge the impact of an ASD difficulty on daily functioning.

Theme 3: Support Experiences

Some of the young adults attended university, and some were in paid employment and volunteer work. Mothers of young adults at university spoke about stressful interactions with university support services. Other mothers spoke of their struggles to navigate access to adult support systems as their children left a funded special education school program. They acknowledged the pivotal role of schools in providing transition support for their children and families, but spoke of strenuous relationships within the school system.

School Support

Some mothers revealed their lack of confidence in school systemic procedures in facilitating transition support to post-secondary education. For example, Carol experienced challenges in accessing an academic pathway for her son Adam in high school. It would seem that the school had determined her son's ability was situated in a vocational trade:

> Come to Year 12, the principal sat all the kids down and said because the high school got bad marks last year we really don't want you guys doing VCE [Vocational Certificate of Education] this year unless you're basically acing all the subjects because he was scared - the principal was - of losing his job (Carol, 23-31).

It is likely that due to previously low academic results, the principal chose to allow high achievers in an academic pathway in an attempt to lift the school profile. However, the impacts of the broader decision on Adam as an individual is compromised. It is unclear whether Adam's ASD had a role to play in this decision of a vocational pathway. He appears to be caught within a whole-of-school systems initiative of improving current school performance that failed to support him as an individual:

> That was the start of huge problems that I had up there because I said Adam has so much potential. I've had to fight all of his life to get him to the point where he is right now and because of your selfish actions you're hindering his future…I said if you give Adam the tools, the keys to learn how to study and know how to organise himself in Year 12…He would've passed it (Carol, 33-39).

Carol's tone is desperate as she advocates for a better future pathway for Adam at the school. Her angst and desperate tone suggest the hurdles she has overcome over time for Adam to be successful at school. Mary shares a similar experience to Carol with her son Tim. In high school, Tim was moved from an academic to a vocational pathway. His experience at school was:

> They had told him that he had fallen behind in English and in his English work, in his English homework, and so he no longer did the HSC [High School Certificate] stream for English. He did the Life Skills stream for English. He was quite upset because some of the work he said was easy, and the other people in his class weren't of his - like the same ability as him (Mary, 108-114).

In both Carol and Mary's lived school experiences, their sons were perceived as non-academic students. However, Tim was conscious of his capability and felt uncomfortable in a lower English stream. It might be that with support in mainstream English Tim would be successful. However, he was not provided with that option. In Carol's observation of her son's experience:

> It was more dumbing down. It didn't help Adam at all. It didn't - Year 12, whole year for Adam, was a waste year because he stopped learning, he

> stopped stretching himself…They could've spent that time helping them learn how to do a budget, what is a budget, in life what kind of bills you may need, what's the importance of having ambulance insurance…But nothing was done, nothing (Carol, 435-472).

Carol had expectations of Adam learning life skills in the vocational class, however this was not the case. Her angst reverberates in tones of negativity and hopelessness as she reflects on a wasted school year for Adam. Additionally, Adam was required to do a work experience placement as part of the vocational pathway. Carol's experience of the school accessing work for Adam was as follows:

> The principal knew this other man through his football connections and wanted Adam to go work at this caravan place where they fix up and do old caravans up and sell it. But obviously the owner of the caravan place had some sort of nasty background because he had firearms and he had drugs and other things there. It just wasn't okay (Carol, 213-218).

Carol is aware of limited workplaces in her small rural country town. However, she did not expect Adam to be situated in a work environment that was threatening and unsafe. As a result, she was proactive in accessing work experience for Adam at her husband's place of work:

> Because he was doing the VCAL [Vocational Certificate of Applied Learning] thing, we had to try and find him one-day-a-week work so he then decided to work. I got him work where my husband works. So, he was doing that one-day a week with high school VCAL (Carol, 151-155).

Carol's experience in transitioning her daughter Addie to university was complex. She mentions the support from school:

> Her transition from high school- I had gone to numerous meetings with them in year 12 and the previous year to try and help her. They didn't help her with any of the university forms or any of the scholarships so she missed out on all the scholarships. It's just been extremely stressful - a nightmare to tell you the truth (Carol, 43-45).

Carol's lived experience of a small country school in rural New South Wales reflects limited specialist support services at school for both of her young adult children on the autism spectrum. It would seem that the school did not acknowledge her perception of her children’s abilities and as such no assistance was provided for them to access post-secondary education. Her fluctuating stress levels and challenging experience conveys her sense of disillusion and helplessness. Similarly, Lua’s son Bob experienced limited support from his school, but with a difference:

> Because I'm a teacher myself he was in lucky position that I was aware of certain things that I could do. So, I would do it for him, but the school itself didn't actually pick it up. Because he had distanced himself from the unit they didn't push to come back in to help him in that transition. So, it was pretty much, me helping him through everything (Lua, 139-145).

Contrary to Carol, Lua’s experience as a teacher came in handy as she persevered with Bob’s support at high school. It is likely that Lua’s insider teacher knowledge of school support processes and systemic procedures assisted with Bob’s access to university.

Post-School Support

Of the seven young adults on the autism spectrum, Addie, Bob, Kay, and Vanessa attend university, whilst Tim is at TAFE, Adam is in paid employment, and Matt is in volunteer work. From the mothers’ perspectives, it would seem that access to support after school was sporadic. Carol, Lua, and Mary spoke of hurdles with university support systems, whilst Sue appeared accepting of the minimal support that Matt received.

Carol expresses the challenges she experienced in accessing support for Addie at university:

> However, calling up [University A] they informed me there's a program for challenges and disabilities in people called equity and diversity. I spoke to the lady. The lady basically said, Addie should go to a TAFE and not even bother with university (Carol, 47-68).

The tension appears to be heightened in Carol’s experience below:

> Unfortunately, Addie is now at university and the very first meeting Addie had with this lady, the lady turned around and said to Addie to her face, why are

> you even coming here? Why aren't you doing something closer to where you are? We live in the country so there are no other universities (Carol, 88-93).

Carol’s tone is desperate as she is exposed to negative interactions with support services at the university. Attending university ought to be a pleasant adventure, however, Carol’s use of “*unfortunately*” is an indication of her underlying stressful encounter with the equity support unit. In this instance, the equity staff made a judgment on where Addie should pursue her studies and would seem that Addie’s ASD is perceived as a limitation on her academic ability and future success at university. The suggestion to attend a TAFE college rather than continue studying at university is disparaging, moreover, as this judgment was made in the absence of any personal knowledge or experience of Addie’s capabilities.

In a similar vein, Lua was unaware that support services were available for Bob at university. It was only when he experienced a meltdown as she mentions, that Lua pursued support options:

> There were big stumbling blocks. We weren't aware of the equity department. We got to university and we dropped the ball. In the first probably six weeks we noticed there was a huge - he just wasn't coping. He wasn’t going to lectures. He wasn't engaging with his studies (Lua, 148-155).

Interestingly, both Carol and Lua are proactive parents in supporting their children transition to university. However, both were unaware of support services available at university. It might be the case that the role of support services for students with disability is not clearly articulated through the application process or indeed, in university policies and protocol. Here Lua notes the difference in types of support at university when compared to the support at the school level:

> When he got to university that level of support is no longer valid. It's not there. There's only certain things that they can do, like they can give you extra time to do an assessment, alternative venues…it was definitely a lot less supportive in the university sector to the point that he struggled (Lua, 160-170).

As noted by Hoogsteen and Woodgate (2013) ASD is often perceived as an invisible disability, typically not identified by physical appearance. Therefore, it is unclear as to whether the alternate support options that Lua refers to are reflective of support provided to students with visible disabilities, for example, students with a physical disability requiring wheelchair access. It might be the case indeed, that ASD specific support in the area of social communication skills or daily organisation, for example, may be required for Bob to be successful at university, and in this instance, has been overlooked.

As a single parent Mary's situation is such that her young adult children attended school and university near her workplace that is one and a half hours away from their regional residence, due to their difficulty navigating transportation. Consequently, support services for them are limited, as access to disability support is based on a residential address and allocated within the local suburb:

> Then when I realised that I couldn't access any services except near our permanent address…and to access the counsellors I would have had to give up half a day or even one day of work to get to the counsellor in time. I did take him to a private counsellor but he was very expensive (Mary, 33-38).

Due to government policy on access to disability support Mary is forced to seek private counselling for Tim. Indeed, this impacts negatively on her personal finances. She experiences a similar challenge in accessing employment support for Tim since he attended university out of their local suburb:

> Whilst there, we wished that we could access counselling or job services but we can't, because he was travelling from home to that place in the south-western suburbs (Mary, 171-173).

On the one hand, Tim is faced with a loss of access to counselling and employment support services. On the other hand, as a single parent, Mary faced a difficult choice of losing a half-day of work or pay for private counselling services for

Tim, both of which would have a financial impact on her. She explains a similar situation with access to hospital services:

> But one particular case we were near the emergency services of the hospital and my son had self-harming issues, due to not being able to fit in that high school. We did get into emergency but even then, when the mental health services rang me at work and said they'd had a referral, they said, you live too far away. We can't take you because of your address (Mary, 50-57).

Mary is in a tenuous position as a single parent, as she juggles working far from home with finding schools and university close to her place of employment so that her children can travel safely with her. Because of the complexity of the situation, Tim is denied access to medical, counselling, and employment support services.

In Sue's experience, she engaged with disability employment services to pursue options for Matt. She displays this attitude towards Matt's employment options:

> We have just had discussions with them about having a supported wage situation where if he gained paid employment he may be paid at a lower rate to reduce the stress on productivity and stuff. I don't see the point in him being put into a situation where he's stressed out about performing, just so that he can get paid the same rate as everybody else (Sue, 117-123).

Sue is aware of Matt's ability and the level at which he can be productive in the workplace. Here, Sue places value over her son's happiness in working to his ability in the workplace as opposed to the high wage he might earn.

Summary

Carol, Lua, and Mary experienced fractured relationships with their children's high schools. Post-school transition support from schools appeared challenging for all mothers and Carol found it especially difficult sourcing work experience for Adam in a small country town with limited workplaces. Navigating support services at university was a difficult experience for both Carol and Lua. Of note is Sue's frank attitude in negotiating employment for Matt with disability employment services. She acknowledged Matt’s limited work productivity, and admits to favouring his wellbeing over a competitive high pay. Indeed, Henninger and Taylor (2014) found that parent’s perception of a successful transition to adulthood was described subjectively as their child reaching their full potential whether in the workplace or living away from home.

Theme 4: Family Advocacy

As can be seen all respondents to this study were mothers. Within the family unit, mothers appeared to be active advocates for their young adult children and were persistent in chasing employment opportunities and liaising with support services to ensure their children’s needs were visible and were being met. Lua and Carol struggled to navigate peer influences, socialisation, and alcohol use by their sons.

Mothers’ Persistence

Carol sourced employment for Adam after high school at her husband’s place of work. Adam’s experience at this place of employment was:

> There were different shift times - Adam was supposed to have a supervisor to help and show him how to do certain things but he never actually did. Adam was finding that very difficult and challenging because he had to try and think how to do the job himself. He was always complaining about that because no one's really showed him how to do it (Carol, 249-256).

On the one hand, Carol was successful in securing employment for Adam. On the other hand, the provision of a meaningful work experience was impeded by a lack of staff resources to supervise Adam’s placement. It is unclear as to whether the employer was informed or indeed aware of managing employees on the autism spectrum. It is likely that with a supervisor’s support and explicit instructions Adam might have had a rewarding work experience. In a similar vein, Lua’s interaction with disability employment services is as follows:

> They just didn't seem very organised. They had said to him, what about packing shelves? As I said my son is very intelligent. I've got to admit I was the really narky parent. I said, hey, he's more capable then that. It's not a good option. It turns out I was right…he quit…he was telling me how boring it was and he wasn't challenged (Lua, 217-219).

Lua was an active advocate in liaising with the employment services to pursue work suited to Bob's ability. Nevertheless, Bob changed employment service providers, and his time spent in between finding a job was as follows:

> Played computer games. Slept, ate and played computer games. I found it very, very frustrating. As I've said, I know what my son is capable of. I just felt he was wasting his life (Lua, 239-242).

Here Lua vents her frustration, and her repetition and tone of helplessness is an indication of her disappointment both in the employment service providers as well as in Bob's complacency. However, Lua perseveres in seeking financial support for Bob:

> He receives a pension from the Department of Social Security. He's got a transition plan with them. I always go in with him. I am the person - if anything needs to happen I'm the one that does it for him (Lua, 461-473).

Lua's tone is resounding as she emphasises her responsibility in managing Bob's support through the department of social security. Her repetition of "*I*" demonstrates her priority in ensuring Bob receives the disability pension. In addition, she is proactive with support services at university:

> The problem with the university was that he had to actually go and fill in paper work to apply for an extension prior to its due date, which doesn't help him with his ASD. It ended up being I became a co-person on his things. So, if I knew he had something due I would then put in the paperwork on his behalf in the week beforehand when he has his little meltdown (Lua, 171-187).

Lua perceives her role as co-person signatory as a guarantee that Bob will be on track with his studies. In this way, she assumes responsibility for Bob's organisation, success at university by liaising, and communicating regularly with support services. However, she also reflects on times that are challenging:

> I find sometimes, especially with Bob, there's a lot of times I just give in because it's easier. I'll take over because he just doesn't want to do it. He'll stand there looking at you and you'll be standing there looking at the people and you're like, fine. I'll do it (Lua, 564-568).

Lua's tone is despondent. Whilst she advocates for Bob, here her response has an underlying tone of frustration. In a quiet moment, she is reflective and reveals this about Bob's father:

> He doesn't fall back on his father as much. His father had a lot of problems when Bob was first diagnosed. Dad wasn't very accepting of it and felt that if he pushed Bob certain ways, Bob would just snap out it, Bob would be cured. His dad has a habit of referring it back to me, ask your mum, see your mum, get your mum to do that (Lua, 622-623).

Lua's perseverance, advocacy and management of Bob's life journey are revealed as an unspoken in this extract. This narrative would refer to many years (Bob is now 24) of managing the father's denial of Bob's diagnosis in childhood, captured by the father's perception that somehow Bob's ASD would go away. Here Lua provides an insight into her resilience and the many hats she wears, both as a mother and father, advocate, as well as primary caregiver to Bob.

Supported Social Interaction

Mothers spoke of their children's social activities with trepidation. It is as though these mothers are managing an internal dissonance of a natural transition to young adulthood in socialising with peers, whilst at the same time managing the hidden difficulties of ASD that do not disappear in adulthood. Their voices speak about alcohol and safe behaviour, but their hearts have a plea about deeper issues of their children's ongoing social anxiety, fractured adult interactions, and misunderstanding of body language within a social realm.

Lua expresses concern for Bob's safety as he experiences the social aspect of young adulthood and engages with alcohol:

> I had a concern there for a period because he had started drinking quite heavily when he did go out. I sort of mentioned to him that I'm not happy with this drinking stuff, because I had actually read in research that there's a high incidence of alcoholism on the autism spectrum because they use alcohol and drugs to mask their behaviours. We sat down and we had a very serious chat about that (Lua, 352-357).

Lua is explicit in her conversation with Bob about not being happy with his excessive drinking. Additionally, she provides an insight into how alcohol may be used to alleviate his anxiety when out with peers. Lua's concerns resonate with Carol as she explains her angst as Adam socialises with friends:

> He does find it difficult though to read danger situations, so that's why it was always very concerning as a parent if he wanted to - because he's now 20 - to go off with his mates, to go out to nightclubs and things like that because drinking alcohol and then getting into fights and things like that. He needs to be aware that alcohol can affect your thinking and because he finds it hard to read body language and danger situations that these are more of a concern for me (Carol, 280-286).

In a similar vein, both Lua and Carol's thoughts are intermingled with social and communication challenges of ASD as well as an underlying innuendo of "*letting go*" as their sons navigate a social pathway into adulthood. In both their perceptions their fear lies in the potential violent outcomes of miscommunication fuelled with alcohol.

Through a different lens, Bob has a partner and has explicitly said to Lua:

> He has asked me not to tell her that he has ASD. He doesn't want her to know (Lua, 276-283).

It might be the case that Bob is fearful if his ASD is made known to his partner, he might be seen as different or indeed incapable. Lua admits that Bob is resistant to socialising with friends:

> But one of the girlfriends - he'd been asked to go out one night with them and he'd said no. His girlfriend Sue got very upset. She wanted to go out. Bob said, no, no, he didn't want to go out…He goes with a great deal of upset-ness and displeasure (Lua, 374-391).

However, now that he has a partner, Bob may be perceived as the odd-one-out if he refuses to socialise with the group of friends. This peer pressure combined with his social anxiety may be a trigger for him to use alcohol as a self-soothing agent.

In a similar vein, Carol reflects on Adam's relationship with a partner:

> He had a girlfriend last year. Unfortunately, she became very aggressive and it was very draining. Being the first girlfriend, he found the whole process overwhelming. When he was going out to nightclubs, she would be there and she would tell different men to try and knock him or push him or try to threaten him and cause fights (Carol, 320-328).

In Carol's observation, it is likely that Adam's girlfriend is displaying aggressive behaviour in response to the break-up with Adam (Arnett, 2014). For Adam, this might be a situation where he cannot comprehend her aggression towards him. An underlying innuendo here from Carol's perspective is the potential danger to Adam whilst out socialising, as she has mentioned previously he has difficulty reading social cues, in particular with regards to dangerous situations.

In an attempt to make meaning of ASD and its impacts, Lua is explicit in crafting awareness with Bob in this example below:

> I do know that people on the autism spectrum won't look at people in the face for example. Because things like, you're a young adult, you are out on the town, something happened around the corner, police officers approach. Who are they going to trust? They're not going to trust the boy that's doing this, looking around the room or looking past them or looking at their feet (Lua, 522-544).

Here Lua positions difficulties in social skills and communication associated with ASD within a real-life context. In a vivid description, it can be seen how avoiding eye contact may be misconstrued as avoidant or indeed deceitful behaviour. Within this social context, the legal ramifications for Bob could be potentially harsh.

Summary

Mothers appeared persistent in the pursuit of support, be it, in employment, financial, or emotional. In their lived experiences, they were aware of ASD impacts on their young adults' ability to progress independently. As such they assumed the role of active advocates in taking charge of pathways to adulthood. Lua was proactive and persevered as a guarantor for her son to access university support services as well as accessing the disability support pension. Themes of developmentally typical young adult behaviour and socialisation were interwoven in both Carol and Lua's experiences of their son's social interactions and relationships with partners.

Discussion

The purpose of this chapter was to address the research question: *What are the experiences of parents of young adults on the autism spectrum during the transition to adulthood?* IPA was chosen as the methodology as it allowed parents to reflect on and make sense of their lived transition experiences through in-depth semi-structured interviews (Smith et al., 2009). Through the lens of Bronfenbrenner's Ecological Model (1994) parent transition experiences between multiple microsystems in interactions with the school system, post-secondary activities of education and employment, independent living arrangements, and friendships were also explored within the mesosystem. The findings from this Study 2, and the previous Study 1, were used to inform the development of the quantitative pilot longitudinal survey in Study 3, which will be reported in Chapter 5.

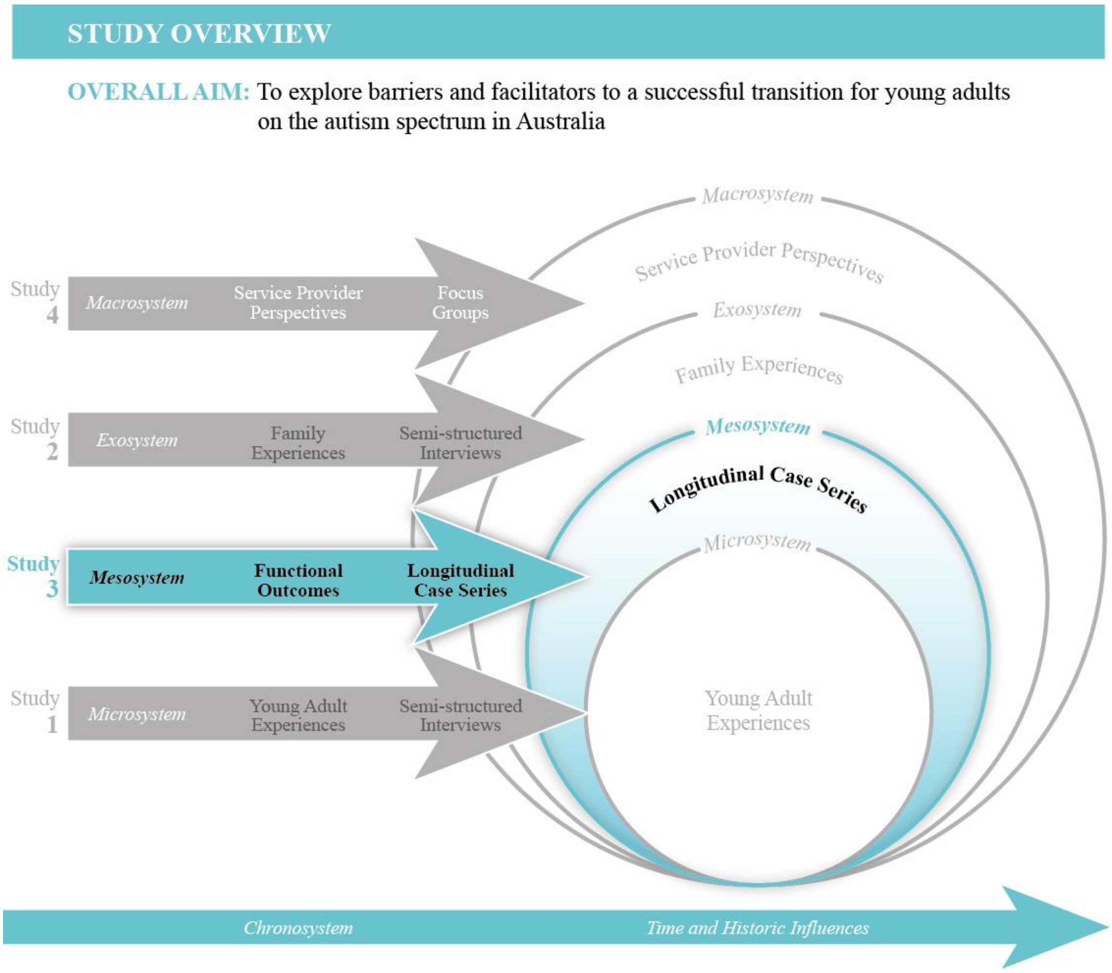
The present study identified four main themes from mothers' experience of the transition process, each with two subthemes. The four main themes were, *Family Challenges, Functional Independence, Support Experiences, and Family Advocacy.*

Within the main theme, *Family Challenges*, there were two subthemes, informed by specific lived experiences relative to mothers' interactions within the exosystem. Within the subtheme of, *ASD and External Impacts*, some mothers were desperate in their attempts to maintain a financial and emotional balance in managing their households. Through the lens of Bronfenbrenner's Ecological Model (1994) across the chronosystem, over time as young adults transitioned to the adult disability support system, many were no longer eligible for disability support. Consequently, within the exosystem of mothers' employment, medical expenses, and counselling intervention for their young adult child depleted their financial earnings to the extent that one mother was reduced to a life choice between food for her family or the Internet. Indeed, these lived experiences are echoed in the literature in that families of individuals on the autism spectrum experienced increased financial needs, and were more likely to stop working in order to meet the support needs of their children on the autism spectrum (Honberg et al., 2009; Kogan et al., 2009; Lord & Bishop, 2010). Moreover, some mothers mentioned being mentally exhausted with some referring to increased hypertension and anxiety. In summary, the underlying tone was one of hopelessness as mothers spoke of sibling tensions, increased responsibility in caring for their young adult children on the autism spectrum, and a sense of being time-poor for themselves.

Summary

This chapter presented the analysis and findings from semi-structured interviews with parents of young adults on the autism spectrum, conducted in Study 2. As part of the exploratory sequential mixed-methods research design used in this thesis, outcomes from the previous study, Study 1, semi-structured interviews with young adults, and outcomes from the present study, Study 2, semi-structured interviews with parents, were used to inform the design of the survey in the case series in the following quantitative study, Study 3. The next chapter, Chapter 5 will present the method, analysis, and findings from the longitudinal pilot case series study conducted in Study 3.

Chapter 5 – Study 3: Case Series Analysis


STUDY OVERVIEW

OVERALL AIM: To explore barriers and facilitators to a successful transition for young adults on the autism spectrum in Australia

Figure 5.1. Flowchart summarising Study 3 case series analysis within the mesosystem.

Background

The aim of the present study was to further examine the qualitative outcomes of Study 1 and Study 2 in a quantitative longitudinal case series study with a target population of young adults on the autism spectrum in Australia currently experiencing the transition process. As mentioned in Chapter 1, this thesis uses a mixed-methods design, specifically an exploratory sequential design. In the exploratory-sequential design, the qualitative findings from Study 1 and Study 2 were used to inform the development of the survey for the present study (Creswell, 2009; Creswell & Plano Clark, 2011). This chapter will present the findings of a pilot repeated measures case series study in which participants were followed over a 12-month period from baseline to follow-up in order to examine potential risk and protective factors associated with successful or unsuccessful transitions during this time.

Quality of Life (QOL) is a multidimensional construct composed of both subjective and objective components and is influenced by personal and environmental factors such as relationships, employment, living circumstances, education, and health (Schalock & Verdugo, 2002). As young adults on the autism spectrum interact within systems, and are influenced by multiple settings across family, school, post-school, community, and disability systems, Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1994) provides a suitable framework within the mesosystem through which both personal and environmental factors associated with QOL can be examined. As discussed in Chapter 2, the mesosystem is defined as the interrelationship between two or more microsystems or settings in which the developing young person is involved and includes the relationship between family experiences, school experiences, post-school opportunities, community access, and support experiences. Thus, within the present study, the mesosystem is a suitable lens through which transition experiences across multiple systems can be viewed.

An individual is more likely to experience a high QOL if important needs in major life settings of education, work, home, and community are fulfilled (Gerhardt & Lainer, 2011; Roux et al., 2013). However, as discussed in Chapter 2, the majority of individuals on the autism spectrum with average to above average intellectual ability experience poor outcomes in adulthood as they remain without appropriate support services, effective interventions, are employed in low paying menial jobs and are dependent on their families, the state medical, and welfare system (Billstedt et al., 2005; Howlin et al., 2004; Migliore et al., 2012). Given the increase in prevalence in ASD diagnosis in Australia (ABS, 2016) of concern is the increase in the number of adults on the autism spectrum requiring access to an already overwhelmed disability support system. Collectively, it is therefore imperative to investigate factors that would facilitate or inhibit a successful transition to adulthood, specifically for young adults on the autism spectrum, to enable focused goal planning at the school and post-school level, to inform program development for agencies supporting these individuals, and to contribute specialised knowledge to strategic policy development.

As discussed previously, in the exploratory sequential design, the qualitative findings from Study 1 and Study 2 were used to inform the development of a quantitative survey in the current study (Creswell, 2009; Creswell & Plano Clark, 2011). Study 1 explored the transition experiences of young adults on the autism spectrum whilst Study 2 explored the transition experiences of parents of young adults on the autism spectrum, specifically examining the key areas of transition to adulthood as identified in the literature. These areas included transition support, post-secondary education, employment, family support, independent living, social inclusion, and overall satisfaction with life (Gray et al., 2014; Halpern, 1993; Hendricks & Wehman, 2009; Howlin et al., 2004). Based on the qualitative outcomes from Study 1 and Study 2, key themes associated with transitions are, *Embracing ASD Differences, Social Interaction, Functional Independence, Support Experiences,* and *Employment*. These overall qualitative outcomes of transition experiences from the semi-structured interviews with both young adults in Study 1, and parents in Study 2 are presented in Table 5.1 and informed the nature of Study 3.

Table 5.1

Qualitative Findings from Interviews with Young Adults in Study 1 and Parents in Study 2

Qualitative Findings Main Theme	Qualitative Findings Subtheme	Quantitative Variables
Embracing ASD Differences	• Understanding their ASD Differences	• Protective factor
	• Secondary Difficulties and their Impacts	• Risk factor
Social Interaction	• Friendship	• Social Belonging/Community Integration
	• Communication	• Risk/Protective Factor
Functional Independence	• Family Support	• Family Support
	• Self-advocacy and Success	• Empowerment/Independence
Support Experiences	• School Support	• Protective factor
	• Post-school Support	• Protective factor
Employment	• Access to Employment	• Competence/Productivity
	• Family Advocacy in Seeking Employment	• Family support

Qualitative outcomes from Study 1 and Study 2 highlighted main themes of, *Embracing ASD Differences, Social Interaction, Functional Independence, Support experiences, and Employment,* as areas of importance to successful and unsuccessful transition, which are constructs intrinsically related to QOL. The Quality of Life Questionnaire (QOLQ: Schalock & Keith, 1993) measures subjective indicators of living circumstances, education, relationships, and wellbeing, and objective indicators of employment, income, and social interactions in key domains of satisfaction, competence and productivity in access to employment, functional independence in daily activities, and social belonging. Thus, the main themes emerging from Study 1 and Study 2, overlap onto the four domains within the QOLQ, and will be used as a proxy to further examine the key factors associated with successful and unsuccessful transitions as identified in Study 1 and Study 2.

Within the QOLQ, access to employment is linked directly to the competence and productivity domain, functional independence within the empowerment and independence domain, social interaction within the social belonging domain, and overall, and ASD differences and support experiences within the satisfaction domain. As such, the QOLQ measures the functional outcomes of the four domains. First, for example, perceptions of successes and challenges in daily life, family interactions, and living circumstances are measured within the Satisfaction domain. Second, skills training gained through education to be able to access, maintain, and feel productive in employment are measured in the Competence and Productivity domain. Third, the ability to make choices, budget finances, and organise daily living activities are measured within the Empowerment and Independence domain. Fourth, participation in social and recreational activities with friends, neighbours, and the community is measured within the Social Belonging domain. Thus, QOL is closely inter-related with a successful transition to adulthood, conceptualised as post-secondary education completion, competitive paid employment that leads to financial security, independence in daily living skills, a supportive social network, and a sense of accomplishment (Hendricks & Wehman, 2009; Lawer et al., 2009; Taylor & Mailick, 2014; Wehman, 2006).

Given the link between good outcomes in adulthood and overall personal wellbeing, QOL will be used as the key outcome variable of interest and a proxy for successful transition in the current study. Further, transition support and intervention, post-secondary education engagement, competitive paid employment, functional independence, and social support will be used as potential predictor variables of successful transition.

Social support is perceived as a coping resource that functions as a buffer against life-stresses, enhances self-esteem, and a sense of belonging, and is closely linked to physical and mental wellbeing (Alvarez-Fernandez et al., 2017; Uncino et al., 2012). Based on the key themes associated with successful and unsuccessful transitions from Study 1 and Study 2, support from family and access to peer social networks emerged as a common theme to improved self-esteem, access to employment, and level of independence, across both young adult and parent participants narrative. First, with respect to family support, parent and sibling support were associated with improved access to employment, learning daily living skills such as budgeting, and managing their ASD differences such as making eye contact when speaking to people. Second, with respect to peer support, some young adults in Study 1 experienced an increased self-awareness in understanding and embracing their ASD differences through involvement and interactions in peer support groups. As such, their self-efficacy in actively pursuing friendships and forming online ASD support groups appeared to improve their social support and increased their self-esteem. Conversely, for other young adults in Study 1, limited access to friendships and negative social interactions associated with communication misunderstandings led to loneliness, isolation, and decreased self-esteem. Therefore, support from family and peers were identified as an important factor to successful transition in Study 1 and Study 2. As such, the association between levels of perceived social support and successful transition will be further examined in the present study.

Study Aims

Study 3 had two specific research aims. First, it aimed to examine whether QOL and key variables such as social support and environmental contexts (e.g., employment, post-secondary education, and functional independence) changes over the 12-month transition period for a sample of young adults on the autism spectrum. No specific hypotheses were made regarding this research question. Rather, this research question was exploratory in order to understand what happens over a 12-month period, and to aid in understanding what successful and unsuccessful transition may look like in different individuals.

Second, it aimed to identify potential factors evident during the transition period for this sample that might be related to a successful or unsuccessful transition to adulthood. That is, it aimed to identify factors common to those participants who demonstrated successful (and unsuccessful) transition to adulthood. Based on Study 1 and Study 2 outcomes, it was hypothesised that:

1. Further support would be found for the role of protective factors in promoting successful transition (higher QOL) over the follow-up period. It was expected that factors that increased the likelihood of successful transition (to employment, independent living, social inclusion, good QOL) would include; receipt of transition planning at school, receipt of disability support services (e.g., work experience placement), social skills training, greater social support, and family advocacy.
2. Further support would be found for the role of risk factors in promoting less successful transition (lower QOL) over the follow-up period. It was expected that factors that reduced the likelihood of successful transition (e.g., to employment, independent living, social inclusion, good QOL)

would include lower functional independence, co-occurring challenges, poorer social skills, and communication difficulties.

Therefore, by following a group of participants over a 12-month period, the present study aimed to firstly understand the transition journey over time, and secondly, to examine the potential risk and protective factors associated with successful or unsuccessful transition during this time. A case series design allowed for a comprehensive examination of participants' journey from baseline to follow up, consolidation of qualitative findings from Study 1 and Study 2, and to inform future large-scale survey studies.

Method

Design

This study implemented a longitudinal case series design to conduct a comprehensive examination of the journey a target group of participants experienced during a transition period. The transition period referred to within the present study is a point within the life journey where young adults between the ages of 18 to 25 years old exit the school system and undertake emergent adult roles and responsibilities within society (Arnett, 2000, 2014; Levinson, 1986). Specifically, this study included a repeated measures case series, with assessments conducted at two time points, that is at baseline and 12-months later. Assessments included self-report evaluations of transition planning and intervention received at high school, engagement in post-secondary education and access to employment, living circumstances, and social support.

Participants

Participants included nine young adults on the autism spectrum living in Australia who completed the online survey between 1 April 2016 and 30 June 2016 at baseline, then a second time between 1 April 2017 and 30 June 2017 at follow-up. Of the nine participants, 22.2% (*n* = 2) were male and 77.8% (*n* = 7) were female ranging from 19 to 25 years of age (*M* = 20, *SD* = 2.22). Inclusion criteria were that participants were young adults on the autism spectrum without intellectual disability (ID), currently experiencing transitions (e.g., to post-secondary education, employment), aged 18 to 25 years old, living in Australia, and completed the survey at both time points. There were no exclusion criteria.

Measures

Based on the outcomes from Study 1 and Study 2, an online survey was designed to measure indicators of successful and unsuccessful transition, as well as individual and clinical characteristics that might act as risk or protective factors to successful or unsuccessful transition outcomes. Specifically, the baseline online survey comprised of three components: (1) The author developed *About You* survey was included to assess for demographics (e.g., age, gender, location) and individual characteristics (e.g., age at diagnosis, receipt of transition planning, other existing challenges), (2) a scale to assess QOL as a proxy for successful transitions, and (3) a scale to assess perceived social support as a possible protective factor.

About You Survey. The author developed *About You* survey was used to collect baseline demographic information including age, and gender as male or female. In this survey, participants were required to provide personal information such as employment status, living arrangements, residential location, and relationship status. Individual characteristics included: (a) Age of diagnosis, intervention received in behaviour support, social skills training, life skills training, and independent living skills, (b) transition planning received at school, individual involvement in transition planning, family involvement in transition planning, work experience placements at school and disability support. All participants completed the survey comprising 36 questions.

In order to establish credibility and trustworthiness with young adults on the autism spectrum, the survey was peer reviewed by a group of four young adults on the autism spectrum, who were also peer researchers at Autism Co-operative Research Council (Creswell & Miller, 2000; Morrow, 2005). Feedback from the peer review process on the author developed *About You* component of the survey suggested gathering further information on participants' daily occupation. Specifically, this led to the inclusion of an additional section asking about the nature and quality of daily activities conducted by the participant (see sections 1.18 *Daily activities*, question 1.19 *What is your daily activity*, and question 1.20 *Please give a brief description of activities you engage in whilst at home* in the survey in Appendix G). In addition, the online survey was piloted with two young adults on the autism spectrum. The two pilot group participants were asked to complete the draft survey and provide feedback on the visual layout of the questions and response format, wording of questions, and clarity of instructions. Feedback from the pilot review was positive with minor suggestions in the wording of three questions. Further, feedback from one community support organisation, Autism Spectrum Australia, prior to advertising on their website, prompted the inclusion of four open-ended questions within the QOLQ, as described below.

Additional Questions. At baseline, open-ended questions enabled participants to provide a text response in the event of any uncertainty of the survey questions asked. The four open-ended questions were as follows:

1. Can you describe how you feel about your life at this point in time?
2. Can you describe how your daily activities/employment make you feel?

3. Can you describe the extent to which you are able to function independently on a daily basis, for example, making your own meals, getting yourself to work?
4. How would you describe your involvement socially with friends, family and the community?

At follow-up, the same online survey was administered, however, in order to gain individual insights into transition experiences over a 12-month time period, two open-ended qualitative questions were additionally included to assess for change in QOL. These were as follows:

1. Over the last year what were some of the positive experiences you have had?
2. Over the last year what were some of the main challenges you have experienced?

The Quality of Life Questionnaire (QOLQ: Schalock & Keith, 1993). The QOLQ is a 40-item self-report scale designed by Schalock and Keith (1993) to measure the QOL of individuals with a disability. The QOLQ consists of 4 subscales, Satisfaction (SAT) as a measure of overall wellbeing with life, Competence and Productivity (CP) as a measure of skills and experiences associated with access to employment, Empowerment and Independence (EI) as a measure of functional independence in daily living skills, and, Social Belonging and Community Integration (SB) as a measure of community integration. Each subscale has 10 items that are rated on a 3-point Likert scale from 1 (low) to 3 (high). Therefore, each subscale has a potential total score ranging from 10 to 30. Total quality of life (QOLT) is computed by summing the 4 subscale scores with an overall potential range of 40 to 120. According to the Standardisation Manual, higher subscale scores indicate higher levels of satisfaction, competence and productivity, empowerment and independence, social belonging, and overall higher QOL (Schalock & Keith, 2004).

The instrument possesses good psychometric properties. Schalock and Keith (2004) report coefficient alphas for the total QOL score as .90 and for each subscale as follows (a) Satisfaction .78, (b) Competence/Productivity .90, (c) Empowerment/Independence .82, and (d) Social Belonging .67. Test-retest reliability for the total QOL score has been reported as .87 and for each subscale as follows (a) Satisfaction .80, (b) Competence/Productivity .96, (c) Empowerment/Independence .83, and (d) Social Belonging .82 (Schalock & Keith, 2004).

There are no published clinical cut-offs for the QOLQ, however, according to the Standardisation Manual (Schalock & Keith, 2004) individuals with disability in semi-independent or independent living, engaged in employment, with increased community integration, with a total QOL score of 80 and above are identified as having a high QOL. Those individuals with disability in supervised accommodation, unemployed, with low levels of satisfaction, and a total QOL score of 79 and below are identified as having a low QOL (Schalock & Keith, 2004).

In order to examine differences during the transition period for participants who showed deterioration and improvement in levels of QOL, in consultation with the instrument authors, a median split of the sample based on total QOL scores was conducted at follow-up (K. Keith, R. Schalock, personal communication, 16 June 2017). Thus, based on the Standardisation Manual (Schalock & Keith, 2004), high QOL was defined as a total QOL score of 80 and above, and low QOL was defined as a total QOL score of 79 and below. Further, it was determined that subscale scores of 22 and above would likely reflect higher levels of Satisfaction, higher Competence/Productivity, greater Empowerment/Independence, and, greater Social

Belonging, whilst subscale scores of 21 and below would likely reflect lower levels of Satisfaction, lower Competence/Productivity, less Empowerment/Independence, and, less Social Belonging (Schalock & Keith, 2004; K. Keith, R. Schalock, personal communication, 16 June 2017). At the time this research was conducted, no specific QOL scale existed for individuals on the autism spectrum (Feldhaus, 2015). As such, the QOLQ was used as a measure in this study as it has been validated for individuals with intellectual and developmental disabilities in Australia (e.g., Eggleton, Robertson, Ryan, & Kober, 1999; Kober & Eggleton, 2005; Rapley & Lobely, 1995), the US and other countries (e.g., Renty & Roeyers, 2009; Verdugo, Prieto, Caballo, & Pelaez, 2005).

The Multidimensional Scale of Perceived Social Support (MSPSS: Zimet, Dahlem, Zimet, & Farley, 1988). The MSPSS is a 12 item self-report scale designed to measure perceived adequacy of social support from family, friends, and significant others (Zimet et al., 1988). The MSPSS has 3 subscales with 4 items per subscale corresponding with Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). Participants are asked to rate items on a 7-point Likert-type scale ranging from very strongly disagree (1) to very strongly agree (7). Total subscale scores are calculated by summing responses to each of the 4 items, then calculating the average score for each subscale. The MSPSS total score is calculated by summing subscale total scores, then computing the average score. Mean scale scores ranging from 1 to 2.9 are considered low support, a score of 3 to 5 is considered moderate support, and a score from 5.1 to 7 is considered high support (Zimet et al., 1988). Higher total scores indicate increased perceptions of social support.

The psychometric properties of the MSPSS have been established. Zimet et al. report Cronbach's alpha for the total MSPSS score as .88 and for each subscale as follows: (a) Support from Significant Other .91 (b) Support from Family .87, and (c) Support from Friends .85. Test-retest reliability for the total MSPSS (MSPSST) score is reported as .85 and for each subscale as follows: (a) Support from Significant Other .72, (b) Support from Family .85, and (c) Support from Friends .75. The MSPSS has been used in research with mothers of children on the autism spectrum (Benson, 2012) and with adult populations on the autism spectrum (e.g., Alvarez-Fernandez et al., 2017; Bruwer, Emsley, Kidd, Lochner, & Seedat, 2008).

Procedure

Ethics approval was received from the University of Southern Queensland granted prior to recruitment (USQ: No. H16REA039) and written permission was granted from the Deputy Vice-Chancellor Students and Communities to recruit participants through USQ Student Services. USQ Student Services shared the survey link to all students registered with them who identify as being on the autism spectrum. Participants were also recruited via *gatekeeper* approvals of different autism support organisations and Internet forums such as, Autism Queensland, Autism Co-operative Research Council, Asperger Services Australia, Australian Autism Asperger Network, Autism Spectrum Australia and Autism Facebook support groups. Administrators of both private and public Facebook forums were contacted to request permission to post recruitment details on their particular online threads. Once gatekeepers agreed to participation in the project, a message was posted to the group through an information sheet, which provided details of the project as well as researcher contact details for those individuals that were interested in participating. Participants were recruited predominantly from Autism Spectrum Australia and USQ Student Services, across

New South Wales, South Australia, and regional Queensland.

All participants who responded to the online study post were provided with a Participant Information Sheet (Appendix H) that gave details of the aims of the project, voluntary participation, withdrawal from the project at any time, as well as researcher contact details for those young adults that were interested in participating. Informed consent to participate in the survey at both time points was tacit, that is, indicated by ticking a consent box in the Participant Information Sheet, then by completion, and submission of the survey. Participants were asked to confirm that they were aged between 18 to 25 years of age, had a diagnosis of ASD without ID, were in the transition period, and were living in Australia. Participants who met the selection criteria were eligible to participate at both time points of the survey, and were asked to provide an e-mail contact address at time 1 (T1) for participation in the survey 12-months later at time 2 (T2). Participants were provided with a pseudonym to provide anonymity. Once the survey was completed, the online responses were saved to a secure server that required security password access, until the completion of data analysis.

Baseline Data Collection. At baseline a total of 16 participants completed the survey and gave consent to participate in the survey at both time points. Three participants were excluded due to being outside of the inclusion age criteria of 18 to 25 years old. As a result, 13 participants were eligible to participate in the survey at baseline and follow-up. See Figure 5.2.

Follow-up Data Collection (12-months later). At follow-up, 13 participants were emailed the survey link. A total of 10 participants responded and completed the assessment therefore three participants were lost to attrition. No significant differences were identified in the three participants lost to attrition to the 10 who completed the follow-up assessment as follows. One of the three participants lived with parents and was engaged in post-secondary education, with the other two participants being unemployed, not engaged in post-secondary engagement, and living in shared accommodation. Further, one of the 10 participants who completed the follow-up assessment was excluded from analysis due to the fact that full data for the QOLQ and MSPSS (key constructs) was missing in their entirety. The final sample for analysis comprised of nine participants with data at both time points. Figure 5.2 provides a visual representation of the selection process for the inclusion and exclusion of data, and the final sample included in the present study.

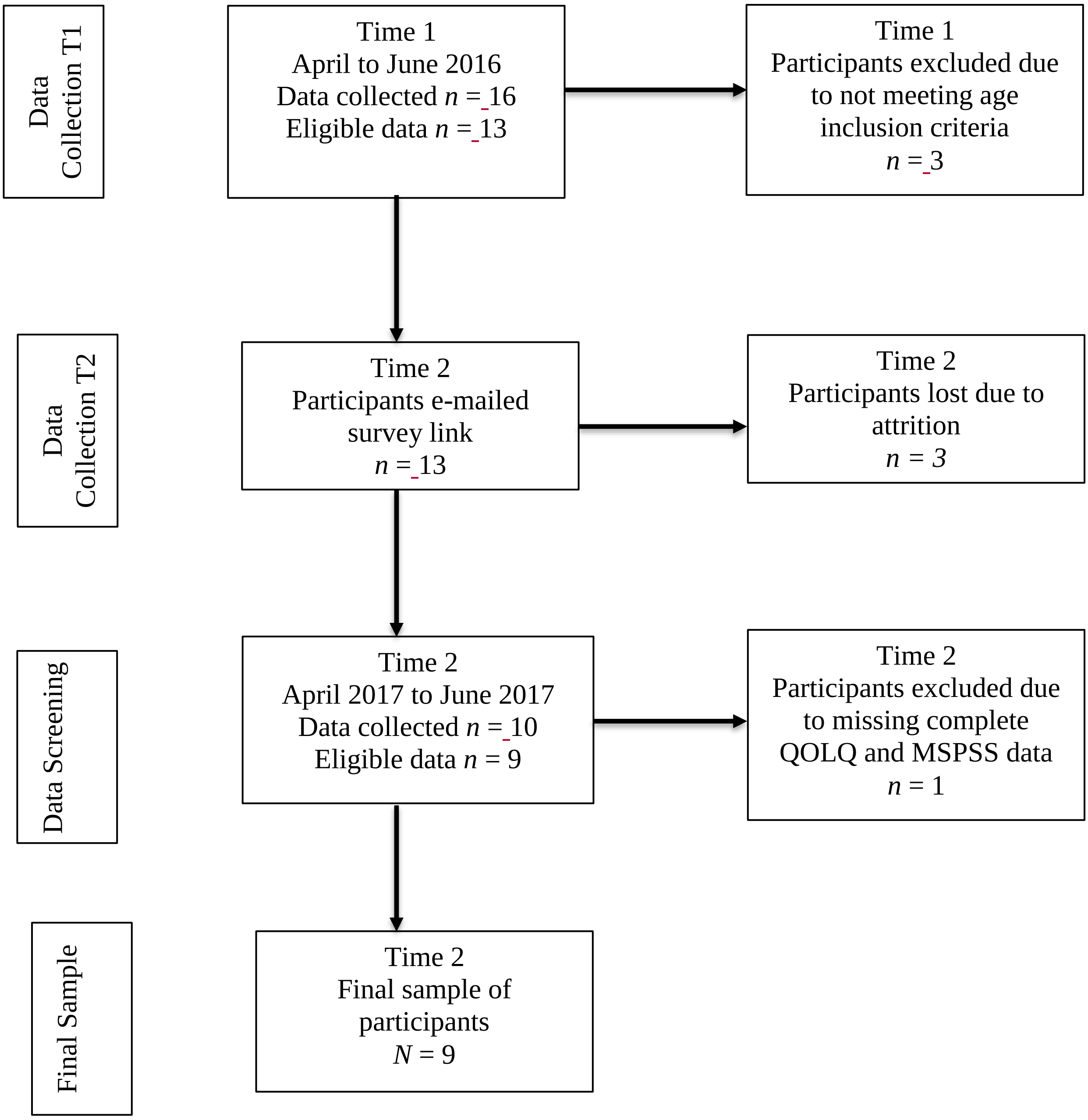


Figure 5.2. Flowchart of data collection process at Time 1 (T1) and Time 2 (T2).

Analytic Strategy

To examine the first research question: *Does quality of life and key variables of social support and environmental contexts change over the 12-month transition period*, the data was analysed in two ways. First, group means on the QOL subscales and total score were examined at baseline and follow-up time points to determine whether measured QOL changed over this period for the group. Second, the Reliable Change Index (RCI: Jacobson & Truax, 1991) was utilised to determine if individual participants showed reliable change on QOL from baseline to follow-up. RCI's provide a measure of statistical significance regarding individual change in scores that takes into account the scale reliability and is beneficial when group sample sizes are small. Positive RCI's reflect increases and negative RCI's reflect decreases in the target score, and an RCI with a magnitude of 1.96 or greater in either direction is considered statistically reliable at the $p < .05$ level (Jacobson & Truax, 1991). Thus, RCI's were calculated for the sample of nine participants for total QOL and the four subscale scores to assess for statistically reliable change longitudinally from baseline to follow-up. Each participant's RCI was then categorised into, *showed statistically reliable improvement*, *showed statistically reliable deterioration*, or *showed no statistically reliable change,* to enable reporting of the proportion of participants showing each type of change during the follow-up period.

To examine the second research question: *What factors are evident during the transition period that might be related to a successful or unsuccessful transition to adulthood,* a series of steps were taken. First, as described above, based on RCI calculations from T1 and T2, individual cases were categorised into reliable change categories and grouped according to those who showed statistically reliable improvement, statistically reliable deterioration, or no reliable change at follow-up. Second, individual cases were then examined within these groupings to further explore risk and protective factors that were evident and potentially related to the key QOL outcome variable. This was achieved by an in-depth case analysis of each participant within these QOL change categories.

In doing so, each case was described in terms of demographic and individual factors, education, support and intervention, QOL, positive experiences, social support, and ASD impact and how these changed over a 12-month time period using RCI's for the key variables of QOL and Social Support. Descriptive data was also supplemented by participant responses to open-ended questions within the survey at follow-up. Common themes were then summarised and contrasted. Therefore, this study explored the similarities and differences evident between participants showing positive and negative change in QOL, in order to provide a preliminary identification of potential risk and protective factors that may be related to a successful transition.

Results

Group Characteristics

To first understand the group as a whole, the following presents descriptive data relating to participant baseline demographics, individual, and support characteristics that might impact on successful or unsuccessful transitions. Baseline demographic and individual characteristics are provided in Table 5.2.

Demographic and Individual Factors. Overall, Table 5.2 shows that the majority of participants (55.6%) lived with parents in the family home, and were single. Results show that one (11.1%) lived with a partner, three (33.3%) lived with friends or roommates, and four (44.4%) were in a relationship. In addition, five (55.6%) received a diagnosis between the ages of 5 to 11 years whilst four (44.4%) were between 19 to 21 years of age, and six (66.7%) received fortnightly disability pension payments and three (33.3%) did not. Responses show that five (55.6%) were engaged in post-secondary education, two (22.2%) in paid employment, one (11.1%) stayed at home, and one (11.1%) did not report. Weekly wages for the two participants (22.2%) who were in employment was over $200 per week, with average hours worked between 20 to 30 hours per week. A detailed summary of baseline demographic information can be found in Table 5.2.

Table 5.2

Baseline Demographic and Individual Factors of Participants at Time 1 (N = 9)

Gender (Age *M* = 21)	*n*	%
Male	2	22.2
Female	7	77.8
Age of Diagnosis		
4 to 13 years	5	55.6
19 to 21 years	4	44.4
Living Circumstances		
Partner	1	11.1
Friends/roommates	3	33.3
Parents	5	55.6
Relationship Status		
Relationship	4	44.4
Married	-	-
Single	5	55.6
Disability Pension		
Yes	6	66.7
No	3	33.3
Current Tertiary Study		
Yes	5	55.6
No	3	33.3
Missing	1	11.1
Program		
University Degree	4	44.4
TAFE	1	11.1
None	2	22.2
Paid Employment		
Yes	2	22.2
No	7	77.8
Job Category		
Vocational Trade	1	11.1
Administrative	1	11.1
No job category	7	77.8
Weekly Pay		
Over $200	2	22.2
No weekly pay	7	77.8
Average hours worked		
20-30	2	22.2
None	7	77.8

Support and Interventions at Baseline. Overall, all participants completed high school with about half, (55.6%) having received social skills training, and access to work experience (55.6%) during schooling. Results show that four participants (44.4%) had a transition plan and five (55.6%) did not. Four (44.4%) reported family involvement in the transition planning meetings. About half of the participants (55.6%) reported receiving work experience whilst at school and only one (11.1%) received support from a disability support provider to access work experience placements whilst at school and post high school. Four participants (44.4%) reported receiving some type of intervention within high school. Of the interventions received at school, two participants (22.2%) received behaviour support interventions, four (44.4%) received social skills training, three (33.3%) received life skills training, and one (11.1%) received independent living skills training. With respect to intervention received post high school, one participant (11.1%) received behaviour support, four (44.4%) received social skills training, two (22.2%) received life skills training, and one (11.1%) received independent living skills training. A detailed summary of participants’ support and intervention can be seen in Table 5.3.

Table 5.3

Support and Interventions at Baseline (N=9)

Transition Plan at School	*n*	(%)
Yes	4	44.4
No	5	55.6
Family involvement in transition planning		
Yes	4	44.4
No	5	55.6
Work experience at school		
Yes	5	55.6
No	3	33.3
Missing	1	11.1
Support from provider post high school		
Yes	1	11.1
No	7	77.8
Missing	1	11.1
Interventions at school		
Behaviour Support	2	22.2
Social Skills	4	44.4
Life Skills	3	33.3
Independent Living Skills	1	11.1
Interventions outside of school		
Behaviour	1	11.1
Social Skills Training	4	44.4
Life skills	2	22.2
Independent Living Skills	1	11.1

Change in Quality of Life from Baseline to Follow-up

To address the first research question: *Does quality of life and key variables of social support and environmental contexts change over the 12-month transition period,* the data is presented in two ways. First, group means and standard deviations were computed for the total and subscale scores on the QOLQ at T1 and T2. Scores are presented in Table 5.4

Table 5.4

Means (M) and Standard Deviations (SD) for Total QOL and QOLQ Subscale Scores

	T1 *M*	T1 *SD*	T2 *M*	T2 *SD*
SAT	19.67	4.89	19.67	5.59
CP	17.11	4.62	19.67	5.07
EI	19.78	4.35	20.89	4.10
SB	20.22	2.99	20.22	2.58
QOLT	76.78	7.88	80.44	1

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB).

Overall, the group as a whole showed some improvement on competence and productivity, empowerment and independence, and total QOL, whilst overall satisfaction and social belonging remained consistently low from baseline to follow-up. Importantly, all subscale scores at both time points were low indicating sub-optimal QOL.

Second, RCI was used to report the proportion of participants making reliable improvement, reliable deterioration, or no reliable change. There was considerable variation in the improvement and deterioration made by individual participants across total and subscale scores. In terms of reliable change on the total QOL, four out of nine participants (44.4%) showed a reliable increase in total QOL, four (44.4%) showed a reliable deterioration in total QOL, and one (11.1%) showed no reliable change. A summary of these findings can be seen in Table 5.5 in addition to descriptions of the level of QOL at baseline and follow-up.

Table 5.5

RCI's for Quality of Life Total Scores (N = 9)

Case	QOLT-T1	QOLT-T2	RCI	Category	QOL-T1 High/Low	QOLT-T2 High/Low
Ms. Katherine	63	87	+19.09	Reliable improvement	Low QOL	High QOL
Ms. Kelly	69	66	- 2.38	Reliable deterioration	Low QOL	Low QOL
Ms. Kylie	85	78	-5.57	Reliable deterioration	High QOL	Low QOL
Mr. Keith	88	96	+6.36	Reliable improvement	High QOL	High QOL
Ms. Lily	79	80	+0.79	No reliable change	Low QOL	Low QOL
Ms. Lavender	75	64	-8.75	Reliable deterioration	Low QOL	Low QOL
Ms. Petal	72	82	+7.95	Reliable improvement	Low QOL	High QOL
Mr. Reggie	79	69	-7.95	Reliable deterioration	Low QOL	Low QOL
Ms. Talita	79	99	+15.91	Reliable improvement	Low QOL	High QOL

Note. RCI = reliable change index values of 1.96 or greater in either direction indicate a reliable change at the 5% significance level or better

For the Satisfaction subscale**,** clinically reliable improvement was evident for four (44.4%) participants with the remaining participants showing reliable deterioration. For the Competence/Productivity subscale, clinically reliable improvement was evident for four (44.4%) of participants, with four (44.4%) participants showing no change and one (11.1%) participant showing reliable deterioration. For the Empowerment/Independence subscale, clinically reliable improvement was only evident for two (22.2%) participants, with the majority, (66.6%) showing no reliable change. Finally, for the Social Belonging subscale, equal numbers of participants (one third) showed reliable improvement, reliable deterioration, and no change. In sum, four participants showed improvement on total QOL and the Satisfaction subscale, whilst three out of the same four participants showed improvement on the Empowerment and Independence, and Social Belonging subscales, and half showing improvement on the Competence and Productivity subscale. Therefore, those participants who showed improvement in total QOL also tended to improve in Empowerment and Independence, Competence and Productivity, overall Satisfaction, and Social Belonging. A summary of these findings is presented in Table 5.6 and Table 5.7.

Table 5.6

RCI's for Quality of Life Subscale Scores Satisfaction (SAT) and Competence and Productivity (CP) (N = 9)

Case	SAT T1	SAT T2	RCI	Category	CP T1	CP T2	RCI	Category
Ms. Katherine	13	18	+3.97	Reliable improvement	11	24	+10.34	Reliable improvement
Ms. Kelly	25	19	-4.77	Reliable deterioration	10	15	+3.97	Reliable improvement
Ms. Kylie	27	24	-2.38	Reliable deterioration	15	14	-0.79	No reliable change
Mr. Keith	24	30	+4.77	Reliable improvement	23	22	-0.79	No reliable change
Ms. Lily	20	16	-3.18	Reliable deterioration	12	23	+8.75	Reliable improvement
Ms. Lavender	20	13	-5.57	Reliable deterioration	20	20	0	No reliable change
Ms. Petal	15	18	+2.38	Reliable improvement	19	18	-0.79	No reliable change
Mr. Reggie	18	14	-3.18	Reliable deterioration	20	15	- 3.97	Reliable deterioration
Ms. Talita	15	25	+7.95	Reliable improvement	21	28	+5.57	Reliable improvement

Note. RCI=reliable change index values of 1.96 or greater in either direction indicate a reliable change at the 5% significance level or better

Table 5.7

RCI's for Quality of Life Subscale Scores Empowerment Independence (EI) and Social Belonging (SB) (N = 9)

Case	EI T1	EI T2	RCI	Category	SB T1	SB T2	RCI	Category
Ms. Katherine	22	25	+2.38	Reliable improvement	17	20	+2.38	Reliable improvement
Ms. Kelly	12	13	+0.79	No reliable change	22	19	-2.38	Reliable deterioration
Ms. Kylie	18	17	-0.79	No reliable change	25	23	-1.59	No reliable change
Mr. Keith	20	20	0	No reliable change	21	24	+2.38	Reliable improvement
Ms. Lily	23	23	0	No reliable change	24	17	-5.57	Reliable deterioration
Ms. Lavender	17	16	-0.79	No reliable change	18	15	-2.38	Reliable deterioration
Ms. Petal	21	25	+3.18	Reliable improvement	17	21	+3.18	Reliable improvement
Mr. Reggie	23	20	-2.38	Reliable deterioration	18	20	+1.59	No reliable change
Ms. Talita	23	25	+1.59	No reliable change	20	21	+0.79	No reliable change

Note. RCI=reliable change index values of 1.96 or greater in either direction indicate a reliable change at the 5% significance level or better

Categories of Change in Quality of Life

As outlined in the Methods section, RCI scores representing change from baseline to follow-up were grouped into three categories, those who improved in QOL from baseline to follow-up (Improvement in Quality of Life), those who deteriorated from baseline to follow-up (Deterioration in Quality of Life), and those who showed no change in QOL from baseline to follow-up (No Change in Quality of Life). An equal number of participants (*n=4*, 44.4%) showed improvement in QOL as did those showing deterioration. No change in QOL was evident for only one participant (11.1%). These QOL groupings were subsequently utilised in the following case series analysis, with participant results discussed according to their QOL status over the 12-month follow-up period.

Case Series Analysis

To answer the second research question: *What factors are evident during the transition period that might be related to a successful or unsuccessful transition to adulthood*, and provide preliminary identification of potential risk and protective factors that might be associated with successful or unsuccessful transition, a case series analysis of the nine participants was conducted. Cases are presented according to QOL change categories to identify potential common factors within each group of participants. Each case is discussed in terms of demographic and individual factors, education, support, and intervention received, QOL, positive experiences, social support, and ASD impact so as to gain a better understanding of how these factors might be associated with successful or unsuccessful transition

Category 1: Improvement in Quality of Life

The following four cases are presented to further examine potential risk and protective factors associated with successful transition to adulthood or improved QOL.

Case 1 - Mr. Keith

Demographic Characteristics. Mr. Keith is a 23-year-old single male who lives with his parents, is employed as a kitchen-hand for 20 to 30 hours a week, earns an income of $200 per week, and receives the disability pension. Mr. Keith received a diagnosis of ASD at the age of 5.

Education, Support, and Intervention. Mr. Keith attended a state high school, received support through the special education program, and completed year 12. At school Mr. Keith received a transition plan with parent involvement in transition planning, and received the following interventions: behaviour support, social skills training, independent living skills, and life skills training. Additionally, he received support through disability employment services and had two work experience placements whilst at school. Mr. Keith has a Technical and Further Education College (TAFE) qualification and reported having received life skills training and independent living skills training post high school. Thus, Mr. Keith has completed his education, obtained additional post-secondary education qualifications, and specific skills to enhance his transition.

Quality of Life. Mr. Keith showed clinically reliable improvement in scores on the total QOL, Satisfaction, and Social Belonging subscales from baseline to follow-up. Scores on the Competence/Productivity remained consistently high from baseline to follow-up, thus indicating that he is confident with the skills and experience required for his employment, whilst scores on the

Empowerment/Independence subscale remained low for Mr. Keith over time. Notably, Mr. Keith did report receiving comprehensive support at baseline, which may have contributed to his high QOL score at baseline. RCI scores for total QOL and subscales from baseline to follow-up are presented in Table 5.8.

Table 5.8

Summary of QOLQ, RCI's, and MSPSS Categories for Mr. Keith

	T1	T2	RCI	Category		T1	T2	T1	T2
QOLT	88	96	+6.36	Reliable improvement	MSPSST	4	7	Moderate	High
SAT	24	30	+4.77	Reliable improvement	SSO	2	7	Low	High
CP	23	22	-0.79	No reliable change	SF	7	7	High	High
EI	20	20	0	No reliable change	SFr	4	6	Moderate	High
SB	21	24	+2.38	Reliable improvement					

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB). Multidimensional Scale of Perceived Social Support Total (MSPSST) and subscale abbreviations, Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). MSPSS scores from 1 to 2.9 indicate low support, 3 to 5 moderate support, and 5.1 to 7 high support (Zimet et al., 1988).

Social Support. Perceived social support scores show an increase on the total Multidimensional Scale of Perceived Social Support score, Support from Significant Other, and Support from Friends subscales over time, whilst Support from Family for Mr. Keith remained high at both time points. Specifically, at 12-month follow-up, Mr. Keith reported that he enjoyed interacting with friends and family on a daily basis and at work he enjoyed meeting customers. In his words, "*I participate fully with friends and family."* Thus, social support appeared to be a particularly positive feature in Mr. Keith's transition, especially support from his family.

Challenges. Scores on the Empowerment/Independence subscale showed no clinically reliable change for Mr. Keith over time, thus indicating Mr. Keith's functional independence in daily living activities remained low. Mr. Keith reported no major challenges, however, he did note feelings of inadequacy in not being able to cook meals for himself. Further, Mr. Keith reported difficulty in accessing transport to visit his Grandmother at the nursing home, which was important to him. In addition, he wished that he could attend more community events, and specifically mentioned music concerts. Thus, it would appear that access to transport and mobility may present some difficulty in achieving functional independence for Mr. Keith.

Positive Experiences. At follow-up, scores on the Satisfaction and Social Belonging subscales showed clinically reliable improvement for Mr. Keith. Indeed, Mr. Keith reported being a volunteer at a day-care centre for children with disabilities. In his words, "*I feel a sense of fulfilment in helping kids, who are having difficulties understanding why they are different because of the ASD."* Thus, it appeared that Mr. Keith experienced meaningful and positive experiences by interacting with, and supporting children on the autism spectrum during the follow-up period.

ASD Impact. For Mr. Keith whilst he reported improvement in QOL overall, and several positive experiences, there were still notable ways in which his ASD impacted his life. Specifically, Mr. Keith reported difficulty accessing transport and attending community events. However, in particular, Mr. Keith reported being happy with his life, satisfied with his work and in his words, he reported that he, "*Enjoys doing the same things every day*." Thus, maintaining a routine was important and beneficial to Mr. Keith's overall QOL.

Case 2 - Ms. Katherine

Demographic Characteristics**.** Ms. Katherine is a 20-year-old single female, studying at TAFE, receives the disability pension, and lives with a roommate. Her daily activities include doing the household chores and seeking employment. Ms. Katherine received a diagnosis of ASD at the age of 19.

Education, Support, and Intervention. Ms. Katherine attended a state high school and completed year 12. At school, Ms. Katherine did not receive a transition plan, but completed three work experience placements, and received social skills training. Thus, Ms. Katherine completed her school education, and is engaged in post-secondary education to obtain specific skills to enhance her transition.

Quality of Life. Ms. Katherine showed clinically reliable improvement for total QOL, Satisfaction, Competence/Productivity, Empowerment/Independence and Social Belonging scores from baseline to follow-up, thus indicating that overall, she is satisfied with her life situation and experiencing an improvement in her QOL. RCI scores for total QOL and subscales from baseline to follow-up are presented in Table 5.9.

Table 5.9

Summary of QOLQ, RCI, and MSPSS Categories for Ms. Katherine

	T1	T2	RCI	Category		T1	T2	T1	T2
QOLT	63	87	+19.09	Reliable improvement	MSPSST	3	3	Moderate	Moderate
SAT	13	18	+3.97	Reliable improvement	SSO	4	1	Moderate	Low
CP	11	24	+10.34	Reliable improvement	SF	2	1	Low	Low
EI	22	25	+2.38	Reliable improvement	SFr	3	6	Moderate	High
SB	17	20	+2.38	Reliable improvement					

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB). Multidimensional Scale of Perceived Social Support Total (MSPSST) and subscale abbreviations, Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). MSPSS scores from 1 to 2.9 indicate low support, 3 to 5 moderate support, and 5.1 to 7 high support (Zimet et al., 1988).

Social Support. Perceived social support scores show an increase on the Support from Friends subscale from baseline to follow-up for Ms. Katherine. At baseline, in her words, Ms. Katherine reported that her friends, "*kinda bully me.*" However, at follow-up Ms. Katherine described her relationship with her friends as *"amazing, they are my everything."* Thus, Ms. Katherine's relationships with her friends appeared to have improved over time.

With regards to relationships, perceived social support showed a decrease in the Support from a Significant Other subscale. In her words at baseline, Ms. Katherine described her life as, "*lonely, due to being single.*" In addition, Ms. Katherine reported at baseline that, "*I rarely interact with others and usually stuff up on social cues.*" Thus, it would appear that Ms. Katherine experienced difficulty socialising and also missed having support from a special person in her life. Perceived social support from family on the Support from Family subscale remained low for Ms. Katherine, whilst the total Multidimensional Scale of Perceived Social Support score remained moderate. Overall, it might be the case that social support from Ms. Katherine's friends could be a buffer in the absence of support from family and a significant person in her life.

Challenges. At baseline, low scores on the Competence/Productivity subscale and the Support from Family subscale, indicated challenges associated with access to employment, and family support. In particular, Ms. Katherine reported two major challenges, first in finding employment, and second, in her relationship with her family. Specifically, Ms. Katherine associated the negative impact of her ASD in social and communication challenges, with limited access to job opportunities, and in her words at baseline, she reported that she was, "*disappointed as I can't find a job and getting nowhere to my goals.*" Further, both at baseline and follow-up, Ms. Katherine reported a difficult relationship with her family as indicated in consistently low scores on the support from family subscale. Specifically, she does not communicate with her mother, and reported, *"We don't talk due to different points of view on how I should live*." Thus, this challenge in relationships with her mother was reflected in consistently low scores on the Support from Family subscale at baseline and at follow-up.

Positive Experiences. At follow-up, scores on the Competence/Productivity, Empowerment/Independence, and Social Belonging subscales showed clinically reliable improvement for Ms. Katherine, thus indicating overall improvement in access to employment, independence in daily living, and increased community integration. Notably, over the 12-month transition period, Ms. Katherine reported being happy as she gained part-time employment as a waitress, and reported earning wages of $100 per week. Thus, Ms. Katherine viewed gaining employment, earning a wage, and integrating with the community as positive experiences at follow-up.

ASD Impact. At follow-up, Ms. Katherine reported a positive attitude towards her ASD. In her words, "*I know who I am now and am a happier, bubblier person*." Thus, it would appear that Ms. Katherine's late diagnosis at the age of 19 gave her a sense of identity in understanding her unique self, and may have contributed to her improvement in QOL over time.

Case 3 - Ms. Talita

Demographic Characteristics. Ms. Talita is a 22-year-old female who lives with her partner and does not receive the disability pension. Ms. Talita is engaged in post-secondary education, is in full-time employment in an administrative role for eighteen months, and receives a wage of over $200 per week. Ms. Talita received a diagnosis of ASD at age 21.

Education, Support, and Intervention. Ms. Talita attended a private high school and completed year 12. However, Ms. Talita did not receive social support or life skills interventions at school. In addition, she did not access work experience placements and was not on a transition plan. Thus, it is likely that as Ms Talita received a late diagnosis post high school, within the Australian school disability support system, she was not eligible for support, interventions, and transition planning at high school (Disability Programs, 2017).

Quality of Life. Ms. Talita showed clinically reliable improvement in scores on the total QOL, Satisfaction, and Competence/Productivity subscale scores. Scores on the Empowerment/Independence remained high over the 12-month transition period, whilst Social Belonging remained low and showed no change. RCI scores for total QOL and subscales from baseline to follow-up are presented in Table 5.10.

Table 5.10

Summary of QOLQ, RCI, and MSPSS Categories for Ms. Talita

	T1	T2	RCI	Category		T1	T2	T1	T2
QOLT	79	99	+15.91	Reliable improvement	MSPSST	5	5	Moderate	Moderate
SAT	15	25	+7.95	Reliable improvement	SSO	7	7	High	High
CP	21	28	+5.57	Reliable improvement	SF	4	4	Moderate	Moderate
EI	23	25	+1.59	No reliable change	SFr	4	3	Moderate	Moderate
SB	20	21	+0.79	No reliable change					

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB). Multidimensional Scale of Perceived Social Support Total (MSPSST) and subscale abbreviations, Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). MSPSS scores from 1 to 2.9 indicate low support, 3 to 5 moderate support, and 5.1 to 7 high support (Zimet et al., 1988).

Social Support. Perceived social support remained high on the Support from Significant Other subscale, and moderate on the total Multidimensional Scale of Perceived Social Support score, Support from Family, and Support from Friends subscales for Ms. Talita. As reported, Ms. Talita required regular assistance from her partner in time management and in organising her daily morning routine that was important to her, as she stated, "*he is my everything.*" Ms. Talita reported having some friends in her previous hometown, however in her new place of living she reported that she does, "*try to get involved sometimes*." Thus, it would appear that Ms. Talita is dependent on support from her partner and this support is important in her successful transition in daily living activities and functional independence.

Challenges. Ms. Talita reported no major challenges, however, she did note some difficulty in levels of stress and anxiety she experienced at baseline, as her employer had high expectations of her in her administrative employment role. However, at follow-up, whilst Ms. Talita reported still feeling stressed, in her own words she noted, "*but overall things are good*." Thus, it would appear that Ms. Talita was able to manage this stress and had adjusted well to her new place of employment.

Positive Experiences. Increased scores on the Competence/Productivity subscale score over time indicated improved access to employment opportunities for Ms. Talita that may have assisted in her successful transition. In particular, over the follow-up period, Ms. Talita reported feeling competent and productive in her new occupation and stated that she," *feels like she is making a difference.*" This was a change from her first assessment at baseline, when Ms. Talita reported being stressed and anxious at her place of employment, in her words, "*there are lots of expectations by the higher up bosses*." During the 12-month transition period, Ms. Talita moved interstate, got married, started a new administrative job, all of which she identified as changes that were positive experiences.

ASD Impact. For Ms. Talita, whilst she reported improvement in QOL, there were still notable ways in which her ASD impacted her daily life. Overall, she reported ongoing difficulty socialising, in time management, and daily organisation that continued to present challenges for her.

Case 4 - Ms. Petal

Demographic Characteristics. Ms. Petal is a 20-year-old single female who lives with her parents. She attends university and receives the disability pension. Her daily activity consists of surfing the web, engaging in online chat rooms, and reading about history. Ms. Petal received an ASD diagnosis at the age of 5.

Education, Support, and Intervention. Ms. Petal attended a state high school and received support and intervention through the special education program. At school, Ms. Petal received a transition plan with parent involvement in transition planning, and received the following interventions: behaviour support, social skills training, and life skills training. Additionally, Ms. Petal completed three work experience placements whilst at high school. Ms. Petal reported that she received social support, and life skills training post high school from her family.

Quality of Life. Ms. Petal showed clinically reliable improvement in scores on the total QOL, Satisfaction, Empowerment/Independent, and Social Belonging subscales, with scores remaining low on the Competence/Productivity subscale over time. RCI scores for total QOL and subscales from baseline to follow-up are presented in Table 5.11.

Table 5.11

Summary of QOLQ, RCI, and MSPSS Categories for Ms. Petal

	T1	T2	RCI	Category		T1	T2	T1	T2
QOLT	72	82	+7.95	Reliable improvement	MSPSST	5	6	Moderate	High
SAT	15	18	+2.38	Reliable improvement	SSO	4	7	Moderate	High
CP	19	18	-0.79	No reliable change	SF	6	6	High	High
EI	21	25	+3.18	Reliable improvement	SFr	5	5	Moderate	Moderate
SB	17	21	+3.18	Reliable improvement					

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB).

Multidimensional Scale of Perceived Social Support Total (MSPSST) and subscale abbreviations, Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). MSPSS scores from 1 to 2.9 indicate low support, 3 to 5 moderate support, and 5.1 to 7 high support (Zimet et al., 1988).

Social Support. Perceived social support scores show an increase on the total Multidimensional Scale of Perceived Social Support score, and Support from Significant Other, whilst Support from Family remained high, and Support from Friends remained moderate for Ms. Petal. In particular, Ms. Petal reported a close relationship with her mother and brother as she stated, “*amazing, especially my mum, and my brother is my main companion*.” She also reported having one friend online, who understood her autism. In her words Ms. Petal reported, “*I’m in charge if I want to socialise or not*”, indicating that Ms. Petal most likely chose times to socialise with her friend in an attempt to manage her friendship. Thus, the close relationship with her family and the support of her friend were important to Ms. Petal.

Challenges**.** Low scores on the Satisfaction, Competence/Productivity, and Social Belonging subscales at baseline indicated that Ms. Petal was unhappy with her overall situation, and had difficulty accessing employment. In particular, Ms. Petal reported being unhappy with her living circumstances, being unemployed, and had difficulty integrating with the community, as she reported in her own words she, “*barely leaves the house.”* Further, Ms. Petal reported that she would prefer to live independently and be in employment. Interestingly, an increase in scores on the Satisfaction, Empowerment/Independence, and Social Belonging subscales was noted at follow-up. Specifically, at follow-up, Ms. Petal reported that she was,” *able to go out shopping, and to the doctor by herself, and am somewhat fulfilled*.” Thus, it would appear that an increase in functional independence in daily activities improved community integration and satisfaction for Ms. Petal, which was important to her overall wellbeing.

Positive Experiences. The only positive experience reported by Ms. Petal was having her friend. As reported earlier, support from her friend was important to Ms. Petal.

ASD Impact. For Ms. Petal, whilst she reported improvement in QOL, and having a friend, there were still notable ways in which her ASD impacted her daily life. Overall, Ms. Petal reported difficulty in making new friends, being lonely, and experienced challenges in, "*being able to socialise properly.*" Thus, it would appear that social and communication challenges associated with ASD had a negative impact on Ms. Petal and her ability to make friends.

Summary

Within the first category of change, *Improved Quality of Life,* all four participants were engaged in post-secondary study, and three out of the four participants reported receiving social skills training and completing work experience placements whilst at high school. The same three participants lived with parents and received financial support in the form of the disability pension whilst the fourth participant lived with a partner and did not receive the disability pension. Interestingly, two of the four participants within this category received a late diagnosis at the ages of 19 and 21 years old, and as such did not receive transition-planning support at school. However, both of these participants shared a positive attitude in embracing their ASD differences as a part of their individual identities and self-worth. Notably, the other two participants within this category who received a transition plan at school also had parental involvement in their transition planning process.

All participants in this group experienced an increase in overall satisfaction with life over time during their transition. Of note, three of the four participants also experienced an increase in social belonging within the community, and two of the four participants demonstrated an increase in competence and productivity in their places of employment. Thus, feeling connected to the community and being able to contribute productively were common to this group of participants who showed improvements in QOL over the 12-month follow-up period. With respect to perceived social support, two participants experienced an increase in support from friends, and two participants perception of support from friends remained moderate over time. Therefore, all four participants noted moderate to high levels of social support. Whilst support from family differed across participants, it was highlighted as specifically important for two participants. Moreover, support from a significant other increased from moderate to high over time for two participants, remained high for one participant, and low for one participant. Thus, whilst social support differed in nature across participants, collectively, high social support of some type was common for all participants. Overall, support from family, friends, and a special person was important for this group who can be considered to have had a positive transition experience.

Category 2: Deterioration in Quality of Life

The following four cases are presented to further examine potential risk and protective factors associated with unsuccessful transition or deterioration in QOL.

Case 1 - Mr. Reggie

Demographic Characteristics**.** Mr. Reggie is a 24-year-old-male, is in a relationship, is unemployed, and lives with his parents. He is engaged in part-time study at university and receives the disability pension. Mr. Reggie’s daily activity includes online gaming, online social interaction with his girlfriend, and sleeping. Mr. Reggie received a diagnosis of ASD at age 11.

Education, Support, and Intervention. Mr. Reggie attended a state high school and completed Year 12. At high school, Mr. Reggie did not receive support or interventions, did not access work experience placements, and did not receive a transition plan.

Quality of Life. Mr. Reggie showed clinically reliable deterioration in scores on the total QOL, Satisfaction, Competence/Productivity, and Empowerment/Independence subscales from baseline to follow-up. Scores on the Social Belonging subscale remained low for Mr. Reggie at both baseline and follow-up, thus indicating ongoing difficulty in community integration throughout the transition period. RCI scores for total QOL and subscales from baseline to follow-up are presented in Table 5.12.

Table 5.12

Summary of QOLQ, RCI, and MSPSS Categories for Mr. Reggie

	T1	T2	RCI	Category		T1	T2	T1	T2
QOLT	79	69	-7.95	Reliable deterioration	MSPSST	6	6	High	High
SAT	18	14	-3.18	Reliable deterioration	SSO	7	6	High	High
CP	20	15	-3.97	Reliable deterioration	SF	7	7	High	High
EI	23	20	-2.38	Reliable deterioration	SFr	5	4	Moderate	Moderate
SB	18	20	+1.59	No reliable change					

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB). Multidimensional Scale of Perceived Social Support Total (MSPSST) and subscale abbreviations, Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). MSPSS scores from 1 to 2.9 indicate low support, 3 to 5 moderate support, and 5.1 to 7 high support (Zimet et al., 1988).

Social Support. Whilst Mr. Reggie's reported perceived social support scores remained high on the Support from Significant Other and Support from Family subscales over time, and his perceived Support from Friends remained moderate, with notable difficulties in this area noted. Specifically, at 12-month follow-up, Mr.

Reggie reported that his girlfriend, a key source of support, moved interstate, and that he lost contact with his friends over the follow-up period, due to his inability to socialise with them. In his words he reported that, "*I will go out with friends about two times a year*" indicating that he did not access support from friends regularly. In contrast, Mr. Reggie reported that his family provided him with encouragement by helping him socialise. For example, he stated, "*They push me do things that I don't like to do, but I have to, like going to my Grandma's birthday.*" Thus, support from family appeared to be encouraging for Mr. Reggie.

Challenges. Low scores on the Satisfaction, Competence/Productivity, and Social Belonging subscales indicated that overall, Mr. Reggie was unhappy with his life situation, and experienced difficulty accessing employment. Specifically, he reported feeling incompetent in enrolling at university and seeking employment. Indeed, Mr. Reggie reported major challenges relating to study and employment. Further, Mr. Reggie stated that, "*I want to move forward but find it difficult to engage with people and businesses*." In his words, Mr. Reggie also reported that he was, *"depressed and unmotivated"* which were additional challenges for him during the transition period. Thus, Mr. Reggie's challenges in communicating and interacting with people, and feeling unproductive in his life appeared to impact his overall mental health and wellbeing during the transition process.

Positive Experiences**.** Mr. Reggie was able to identify some positive experiences during the 12 months. For example, he reported getting his driver's licence as a positive experience, however in his words he also reported," *I don't like going out so I get mum to do errands for me.*" Thus, while he achieved something positive, he was unable to integrate this fully into his daily routine. However, as he was able to book flights and accommodation to visit his partner interstate, Mr. Reggie viewed these abilities as a positive experience.

ASD Impact. For Mr. Reggie, the impacts of an ASD and associated challenges appeared to have a considerable effect on his daily activities. Overall, Mr. Reggie reported ongoing feelings of inadequacy in communicating with people. Notably, communication difficulties are a hallmark of ASD (APA, 2013). Thus, communication difficulties remained a challenge for him. Further, Mr. Reggie appeared to experience some of the negative stigma attached to ASD during the transition period, as he reported, *"People see the diagnosis and think I can't do things*." He reported that this affected his behaviour, and often meant that he asked his mother to contact people at places of importance on his behalf. For example, he reported, "*I get mum to contact places, like the university for enrolment, but then people treat me weird after*." Thus, it would appear that in this case, family advocacy in communicating for Mr. Reggie as a young adult, presented a barrier for him in later social interactions.

Case 2 - Ms. Lavender

Demographic Characteristics. Ms. Lavender is a 19-year-old single female, lives with her parents, and does not receive the disability pension. She is unemployed, not engaged in post-secondary education, and describes her daily activity as staying home with her parents. Ms. Lavender is a volunteer for one day a week in a disability support service. Ms. Lavender experiences anxiety and depression, and received an ASD diagnosis at the age of 4.

Education, Support, and Intervention. Ms. Lavender attended a state high school and completed year 12. At high school, Ms. Lavender received a transition plan with parental involvement in transition planning, received social skills training, and completed three work experience placements.

Quality of Life. Ms. Lavender showed clinically reliable deterioration in scores on the total QOL, Satisfaction, and Social Belonging subscales from baseline to follow-up, whilst Competence/Productivity subscale scores remained low over time. Empowerment/Independent subscale scores remained low over time indicating that Ms. Lavender experienced difficulty in functional independence in daily life activities. RCI scores for total QOL and subscales from baseline to follow-up are presented in Table 5.13.

Table 5.13

Summary of QOLQ, RCI, and MSPSS Categories for Ms. Lavender

	T1	T2	RCI	Category		T1	T2	T1	T2
QOLT	75	64	-8.75	Reliable deterioration	MSPSST	3	3	Moderate	Moderate
SAT	20	13	-5.57	Reliable deterioration	SSO	1	1	Low	Low
CP	20	20	0	No reliable change	SF	4	4	Moderate	Moderate
EI	17	16	-0.79	No reliable change	SFr	4	3	Moderate	Moderate
SB	18	15	-2.38	Reliable deterioration					

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB). Multidimensional Scale of Perceived Social Support Total (MSPSST) and subscale abbreviations, Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). MSPSS scores from 1 to 2.9 indicate low support, 3 to 5 moderate support, and 5.1 to 7 high support (Zimet et al., 1988).

Social Support. Perceived social support scores remained moderate on the total Multidimensional Scale of Perceived Social Support score, Support from Family, and Support from Friends subscales over time, whilst Support from a Significant Other remained low for Ms. Lavender throughout the transition period. Although Ms. Lavender reported being close to her mother, in her words, her mother was, "*angry and disappointed about the fact that I am still unemployed*." Further, she hoped that her involvement with her friends could be better and reported that, "*I adore my friends dearly, but I don't want to burden them.*" With regards to a partner, Ms. Lavender reported that she was, "*unfortunately single*." Thus, it would appear that whilst her social support scores remained moderate, Ms. Lavender would like to be more engaged with her friends, and missed the support from a special person in her life. Further, whilst she was close to her mother, she felt as though she was disappointing her by being unemployed, which impacted this relationship.

Challenges. Low scores on the Satisfaction and Social Belonging subscales indicated that overall, Ms. Lavender was unhappy with her life situation and experienced difficulty integrating with the community. Indeed, in her words, Ms. Lavender reported, "*When it comes to the community I am not very sociable due to my anxiety. A few years ago, it was a struggle to get me to go to the supermarket.*" Further, over the 12-month transition period, Ms. Lavender reported that she was disappointed with her life, felt unsuccessful, and continued to experience anxiety and depression. Thus, Ms. Lavender experienced additional challenges in socialising, and managing her anxiety and depression that appears to have impacted her overall transition.

Positive Experiences. Ms. Lavender was unable to identify any positive experiences over the 12-month follow-up period.

ASD Impact. For Ms. Lavender, the impact of her ASD and associated challenges appeared to have a considerable effect in her daily life. According to Ms. Lavender, she reported difficulty in integrating with the community and in socialising with her friends. In her words, Ms. Lavender reported, "*I have anxiety and depression as well and that factors into my emotions and lifestyle. I can understand why I think and live in a different way because of my diagnosis.*" Overall, although

Ms. Lavender was cognisant of her differences and appeared to embrace them in a positive light, her ASD challenges appeared to continue to impact her in major areas of her life.

Case 3 - Ms. Kelly

Demographic Characteristics. Ms. Kelly is a 21-year-old female who lives with roommates in shared accommodation. She is in a relationship, does not receive the disability pension, is unemployed, and is not engaged in post-secondary education. Ms. Kelly experiences anxiety and received an ASD diagnosis at the age of 13.

Education, Support, and Intervention. Ms. Kelly attended a private high school and completed Year 12. At school, Ms. Kelly did not receive support or interventions and did not access work experience placements. She did not receive a transition plan, and did not receive social skills or life skills training.

Quality of Life. Ms. Kelly showed clinically reliable improvement in scores on the Competence/Productivity subscale, whilst scores on the total QOL, Satisfaction, and Social Belonging subscales showed clinically reliable deterioration from baseline to follow-up, and scores on the Empowerment/Independence subscale remained low over time. RCI scores for total QOL and subscales from baseline to follow-up are presented in Table 5.14.

Table 5.14

Summary of QOLQ, RCI, and MSPSS Categories for Ms. Kelly

	T1	T2	RCI	Category		T1	T2	T1	T2
QOLT	69	66	-2.38	Reliable deterioration	MSSPSST	4	6	Moderate	High
SAT	25	19	-4.77	Reliable deterioration	SSO	4	7	Moderate	High
CP	10	15	+3.98	Reliable improvement	SF	4	5	Moderate	Moderate
EI	12	13	+0.79	No reliable change	SFr	4	4	Moderate	Moderate
SB	22	19	-2.38	Reliable deterioration					

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB). Multidimensional Scale of Perceived Social Support Total (MSPSST) and subscale abbreviations, Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). MSPSS scores from 1 to 2.9 indicate low support, 3 to 5 moderate support, and 5.1 to 7 high support (Zimet et al., 1988).

Social Support. Perceived social support scores showed an increase on the total Multidimensional Scale of Perceived Social Support score and Support from Significant Other, whilst Support from Family, and Support from Friends for Ms. Kelly remained moderate over time. With respect to support from friendships, Ms. Kelly noted specific concerns that appeared to influence her functioning over the follow-up period. For example, she reported difficulty maintaining friendships due to her anxiety and in her words, she reported, "*I'm a bit of a hermit. My anxiety can prevent me from actively keeping friendships*." However, Ms. Kelly did report that she was in a long-distance relationship and found comfort and support in her partner. Thus, social support remained reasonable for Ms. Kelly over the transition period.

Challenges. Low scores on the Satisfaction and Social Belonging subscales indicated that, overall Ms. Kelly was unhappy with her life situation, and experienced difficulty integrating with the community during her transition process. Ms. Kelly reported it particularly problematic that she rarely participated in any social or community activities and that she subsequently was often lonely. Further, in her words, she reported that she was, "*anxious, I feel my life is useless, less successful than others*". Thus, Ms. Kelly's challenges in coping with anxiety and difficulty with social interactions appeared to impact quite substantially on her life situation, overall wellbeing, and happiness.

Positive Experiences. Interestingly, clinically reliable improvement in scores on the Competence/Productivity subscale was noted at follow-up, evident through a change in access to employment for Ms. Kelly. Specifically, over the 12-month transition period, Ms. Kelly moved interstate, lived independently, gained part-time employment in a childcare setting, and reported earning between $100 to $150 a week. More importantly, at follow-up, Ms. Kelly reported feeling happy, and that she had made an impact in the child-care setting. In her words she stated, "*I help them learn and grow. It makes me really happy to know I'm making an impact even if it's a small one*". Thus, it would appear that gaining employment, earning a wage, and contributing meaningfully to the community improved Ms. Kelly's feelings of competence and productivity, which was important to her. However, Ms. Kelly lived independently in her new living circumstances, and, whilst this may be positive, it may present additional challenges for her in functional independence as she is working minimal hours. It is therefore likely that improvement in her productivity in employment did not transfer into her overall wellbeing, perhaps due to the additional difficulties experienced with social support, anxiety, friendships, and community integration.

ASD Impact. Overall, whilst Ms. Kelly was aware of the challenges associated with her ASD, she appeared to embrace them from a positive perspective. In her words Ms. Kelly reported, "*My diagnosis means that I know what's going on with my body and brain. I think being autistic also makes me more sympathetic to the* *struggles of others, but there is still some stigma attached*." Thus, she demonstrates acceptance and understanding, yet identifies that she still experiences stigma associated with ASD. This may continue to contribute to her overall QOL.

Case 4 - Ms. Kylie

Demographic Characteristics. Ms. Kylie is a 25-year-old single female who lives with a roommate in shared accommodation and receives the disability pension. She is unemployed and not engaged in post-secondary education. Ms. Kylie reported requiring prompting from her roommates in organising herself in daily activities on a regular basis. Her daily activity consists of staying home with roommates, playing video games, and watching documentaries. Ms. Kylie received a diagnosis of ASD at the age of 19.

Education, Support, and Intervention**.** Ms. Kylie attended a private high school and completed Year 12. At school, Ms. Kylie did not receive support or interventions, and did not access any work experience placements. She did not receive a transition plan. Thus, it is likely that as Ms Kylie received a late diagnosis post high school, within the Australian school disability support system she was not eligible for support, interventions, and transition planning at high school.

***Quality of Life*.** Ms. Kylie showed clinically reliable deterioration in scores for the total QOL and Satisfaction subscales, whilst scores on the Social Belonging scale remained high from baseline to follow-up. Scores on the Competence/Productivity and Empowerment/Independence subscale remained low for Ms. Kylie over time, thus indicating that Ms. Kylie had difficulty with skills, experience, and access to employment, as well as difficulty with functional independence in daily life activities. Notably at baseline, Ms. Kylie reported high QOL most likely due to high levels of satisfaction and social belonging at baseline

RCI scores for total QOL and subscales from baseline to follow-up are presented in Table 5.15.

Table 5.15

Summary of QOLQ, RCI, and MSPSS Categories for Ms. Kylie

	T1	T2	RCI	Category		T1	T2	T1	T2
QOLT	85	78	-5.57	Reliable deterioration	MSSPSST	4	5	Moderate	Moderate
SAT	27	24	-2.38	Reliable deterioration	SSO	4	6	Moderate	High
CP	15	14	-0.79	No reliable change	SF	5	4	Moderate	Moderate
EI	18	17	-0.79	No reliable change	SFr	4	4	Moderate	Moderate
SB	25	23	-1.59	No reliable change					

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB). Multidimensional Scale of Perceived Social Support Total (MSPSST) and subscale abbreviations, Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). MSPSS scores from 1 to 2.9 indicate low support, 3 to 5 moderate support, and 5.1 to 7 high support (Zimet et al., 1988).

Social Support. Ms. Kylie reported an increase in perceived social support over the transition period as evident on the Support from Significant Other subscale, whilst scores remained moderate over time for the total Multidimensional Scale of Perceived Social Support, Support from Family, and Support from Friends subscales for Ms. Kylie. Whilst Support from Friends remained moderate, Ms. Kylie reported having little involvement with friends apart from her roommate. In her words, "*I am completely content having very little involvement with people. I don't have a drive to be social."* Further, Ms. Kylie reported talking to her parents occasionally, and believed that they, *"still treat me like a child.*" Overall, although social support scores were moderate, support appeared to be limited for Ms. Kylie, yet this did not cause her distress.

Challenges. A decrease in scores on the Satisfaction subscale indicated that Ms. Kylie was unhappy with her life situation over the transition period. In particular, Ms. Kylie reported sensory struggles that impacted her friendships. In her words, she stated that she was, *"considered fussy, not knowing how friendships work, struggling to find the balance between being a pushover and being aggressive."* Further, low scores in Empowerment/Independence over time, indicated that Ms. Kylie experienced difficulty in functional independence in daily living skills. More specifically, Ms. Kylie reported that she was able to do the bare minimum on a daily basis, in her words, she reported, "*feeling frustrated and disappointed."* Thus, a lack of independence in daily living skills and difficulty socialising presented challenges for Ms. Kylie.

Positive Experiences. Despite some struggles with social support, Ms Kylie reported making "*solid friends"* through her online gaming community and feels valued for her contributions to a variety of online networks. She noted this as a particularly positive experience for her indicating the importance of online social interactions for Ms. Kylie.

ASD Impact. For Ms. Kylie, the impacts of an ASD and associated challenges appeared to have a considerable effect on her daily life activities. Ms. Kylie acknowledged her understanding of difficulties associated with her ASD and appeared to be accepting of them. Further, she was able to clearly articulate her self-regulation strategies in managing her ASD challenges through a positive lens. With respect to her ASD, Ms. Kylie reported, "*I actually have an understanding of why I struggle with certain things rather than just thinking I'm a bad or defective person. I also know that if I'm unreasonably angry, I'm probably having a sensory issue and can try to do something about it.*" Overall however, Ms. Kylie continued to experience difficulty in daily organisation and struggled to understand how friendships worked.

Summary

Within the second category of change, *Deterioration in Quality of Life*, a striking finding was that three out of four participants reported receiving no transition support or interventions at school, and did not receive transition plans. This supports the importance of transition planning at the school level for individuals on the autism spectrum. Further, only one of the four participants in this category was in part-time post-secondary education at university, indicating that lack of involvement in post-secondary education could be a potential risk factor for poorer transition. Importantly, the one participant who was at university experienced substantial communication difficulties, particularly with university staff, which hindered his transition. One other participant reported experiencing pervasive anxiety and difficulties interacting with peers, leading to an overall reduced report of satisfaction and wellbeing. Furthermore, for both of these participants, a decrease in functional independence in daily activities was observed over the transition period, along with low levels of community integration and social belonging. Thus, for this group of three participants, lack of transition support and interventions, combined with ASD challenges in communication, social interaction difficulties, and co-occurring depression and anxiety, appeared to be risk factors associated with a low QOL during the transition period.

The fourth participant within this category of change received a transition plan at school, completed three work experience placements, and received social skills training. Whilst this participant had access to such skill building, she also reported ongoing struggles with depression and anxiety, which appeared to dramatically impact her functional independence and ability to integrate within the community. Further, whilst this participant reported moderate support from friends, she longed for more involvement with her friends, and for support from a significant other. Thus, despite the receipt of transition planning and work experience placements, this participant had constant challenges during the transition period, likely due to ongoing mental health difficulties and lack of functional independence. Thus, it may be the case that these additional risk factors may outweigh the benefits of transition planning for some individuals on the autism spectrum, or more specifically, that transition planning for such individuals with complex needs should be targeted and individualised in their support.

All participants in this category experienced a decrease in overall satisfaction with life, whilst scores on the competence and productivity subscale remained consistently within the low range for all four participants. Thus, feelings of competence and productivity may be particularly important in promoting successful transition and improved QOL. There was one exception for one of the participants, such that a change of living circumstances interstate, gaining part-time employment, and earning a wage, led to improved competence, productivity, and overall self-esteem at follow-up. Notably, these changes were quite recent and would suggest that whilst this participant accessed part-time employment which made her feel valued, it is likely that she was still adjusting to new independent living circumstances, integrating with the community, and establishing friendships, which may have contributed to her overall difficulty during the transition period.

Perceived support from family varied from moderate to high for all four participants. Whilst support from family was consistently high and important to one of the four participants, he lacked support from a significant other who lived interstate, which he identified as a key source of support for him. Another participant did not perceive support from family as important, and chose to limit interactions with her family. However, the same participant required ongoing support in daily activities from roommates. Thus, support from roommates for this participant played a key role in facilitating daily organisation in functional independence. Overall, it would appear that in this category of change, those participants who lived with roommates required increased support in daily living activities and organisation skills. On the contrary, those participants who lived with their parents appeared to benefit with support and encouragement from family members.

Category 3: No Change in Quality of Life

The following case is presented to further examine potential risk and protective factors associated with successful and unsuccessful transition to adulthood.

Case 1 - Ms. Lily

Demographic Characteristics. Ms. Lily is a single 19-year old female who attends university, lives with her parents, and receives the disability pension. Ms. Lily received an ASD diagnosis at the age of 12.

Education, Support, and Intervention. Ms. Lily attended a state high school and completed Year 12. At school Ms. Lily received a transition plan with parental involvement in transition planning, had one work experience placement, and received both social skills, and life skills training.

Quality of Life**.** Ms. Lily showed no reliable change in total QOL scores from baseline to follow-up, although her subscale profile was more complicated. However, reliable improvement was shown for scores on the Competence/Productivity subscales, whilst scores on the Satisfaction and Social Belonging subscales showed reliable deterioration over time for Ms. Lily. Scores on the Empowerment/Independence subscale remained high over time. RCI scores for total QOL and subscales from baseline to follow-up are presented in Table 5.16.

Table 5.16

Summary of QOLQ, RCI, and MSPSS Categories for Ms. Lily

	T1	T2	RCI	Category		T1	T2	T1	T2
QOLT	79	80	0.79	No reliable change	MSPSST	3	3	Moderate	Moderate
SAT	20	16	-3.18	Reliable deterioration	SSO	2	2	Low	Low
CP	12	23	+8.75	Reliable improvement	SF	2	2	Low	Low
EI	23	23	0	No reliable change	SFr	4	4	Moderate	Moderate
SB	24	17	-5.57	Reliable deterioration					

Note. Quality of Life Questionnaire (QOLQ) and subscale abbreviations, Satisfaction (SAT), Competence/Productivity (CP), Empowerment/Independence (EI), and Social Belonging (SB). Multidimensional Scale of Perceived Social Support Total (MSPSST) and subscale abbreviations, Support from Significant Other (SSO), Support from Family (SF), and Support from Friends (SFr). MSPSS scores from 1 to 2.9 indicate low support, 3 to 5 moderate support, and 5.1 to 7 high support (Zimet et al., 1988).

Social Support. Perceived social support scores remained moderate for the total Multidimensional Scale of Perceived Social Support, and Support from Friends subscales, whilst scores on the Support from Significant Other, and Support from Family subscales remained low for Ms. Lily. Ms. Lily reported recently moving interstate, and that she did not have any new friendships. In her words, she stated, "*The only friends I have are in another state, and they have autism like me, so we really understand each other and get along really well.*" Ms. Lily's inability to have formed new friendships in her new location appeared to be an important factor in limiting her successful transition. However, as her move interstate was only recent, it is likely that building social relationships will improve as she makes new friends, which might impact her overall QOL. Further, Ms. Lily also noted difficulty in relationships with her family, which may have impacted her transition. In her words, she reported, *"My family has started to distance themselves from me, as now I'm older they think I should be grown out of my autism.*" Thus, it would appear that Ms. Lily experienced limited support from her family, most likely due to their misunderstanding of her ASD. It is likely that this may have limited her ability to successfully transition during this period.

Challenges. Low scores on the Satisfaction and Social Belonging subscales indicated that overall, Ms. Lily was unhappy with her life situation, and experienced difficulty integrating with the community. In particular, Ms. Lily reported challenges with social inclusion after having disclosed her ASD at university. More specifically, she reported that, "*I came out about my autism at university last year when I was doing a community services course, and my trainer said I should have hid my autism from her and not told them. Then I was excluded from group activity through the whole course."* Thus, Ms. Lily clearly experienced challenges navigating the university sector associated with stigma relating to her diagnosis. Ultimately, she appeared to be negatively impacted by being socially excluded in this activity whilst at university. In addition, Ms. Lily reported missing her friends in her home town and in her words, she stated, "*When I say I have autism, there are people who back away from me immediately, so I struggle a lot with making friends.*" Thus, it would appear that Ms. Lily experienced several negative experiences associated with stigma and ASD, which ultimately impacted her ability to make friends and engage productively at university.

Positive Experiences. Ms. Lily reported an increase in scores on the Competence/Productivity subscale at follow-up. Of note, over the 12-month transition period, Ms. Lily moved interstate, and was a volunteer at an autism day-care centre working with young children on the autism spectrum. In her words, Ms. Lily reported, "*It just makes me happy helping kids out that are going through the same thing, not knowing how to interact with others or understand humour*." Thus, Ms. Lily reported feeling competent and productive, with increased self-esteem, through this volunteer experience. It is possible that this may have at least in part buffered the effects of the challenges reported by Ms. Lily.

ASD Impact. Ms. Lily demonstrated a positive attitude towards her ASD, as she reported in her words, "*I love spreading awareness about autism and talking about it because I see autism as a part of me not something wrong with me.*" Thus, whilst Ms. Lily was aware of the challenges associated with her ASD in her daily life, she appeared to embrace them from a positive perspective as part of her unique identity.

Summary

There was only one participant who fell into the third category of *No Change in Quality of Life*. Importantly, this participant demonstrated several notable challenges and positive experiences that may have acted as protective and risk factors. Whilst at school, this participant accessed support and intervention in the form of social skills training, a transition plan, and work experience placements. Further, she completed her education through to year 12, and was engaged in post-secondary study at university, all of which seem to appear as protective factors associated with more successful transition. However, the occurrence of several negative experiences relating to stigma and social exclusion related to her ASD disclosure, appeared to impact this participant's ability to socialise at university. Further, stigma associated with ASD impacted her ability to form new friendships interstate. Thus, stigma and socialisation difficulties may have been related to her lack of improvement over the follow-up period, despite the transition support and training she received. This is evident through her overall satisfaction with life, social belonging, and community integration, which all decreased over time. Thus, it would appear that negative connotations associated with ASD had a severe impact on this participant's overall wellbeing.

Interestingly, at follow-up, this participant showed an increase in competence, productivity, and self-esteem, most likely related to being a volunteer supporting children on the autism spectrum over time. In addition, whilst perceived social support from family and a significant other was low, support from friends remained moderate over time for this participant. Notably, this participant remained optimistic in accepting her ASD as part of her unique identity.

Discussion

The overall aim of the present study was to further examine key factors identified in Study 1 and Study 2 as potentially associated with successful or unsuccessful transitions in a longitudinal case series study. The growing prevalence of young adults on the autism spectrum would suggest that a significant group within the community faces a lifetime of disadvantage because of their ASD. Within the mesosystem, continuing trends of poor adult outcomes, financial impact on family, society, and the work force, highlight a need to investigate factors associated with successful or unsuccessful transition to alleviate a dependency on family, the state welfare system, to inform disability policy development and targeted intervention, and potentially improve overall QOL. As the domains of overall life satisfaction, competence and productivity in employment, functional independence in daily activities, social belonging and community integration are closely interwoven with successful outcomes in adulthood, QOL was used as a proxy to examine successful transition to adulthood.

The first objective of this study was to explore whether QOL changes longitudinally over a 12-month transition period for a group of young adults currently experiencing the transition to adulthood. It was first important to determine whether QOL changed over time for participants, and to identify for which individuals QOL improved, deteriorated, or stayed the same. This was important as the first step in identifying which participants demonstrated successful transition as earlier defined. Overall at baseline, only a few participants showed high QOL, with some showing high satisfaction with life, high functional independence, and high social belonging. However, at baseline, most participants in this sample showed low QOL and experienced low levels of satisfaction, low confidence and productivity in skills and experience required to access employment, low levels of functional independence in daily activities, and low levels of social belonging. Therefore, at a crucial point in their lives, most of the young adults in this sample are attempting to navigate challenges associated with transitions with a relatively low starting point of confidence and skills. These findings support previous research with individuals on the autism spectrum entering young adulthood, where the majority reported low QOL, were dependent on family, required support in daily activities, with limited social interaction (e.g., Jennes-Coussens et. al., 2006). Thus, it would seem that there is a gap in transition planning, support, and intervention in preparation for adult roles and responsibilities when exiting high school for individuals on the autism spectrum.

Overall, from baseline to follow-up, the young adult group as a whole showed some improvement on competence and productivity in access to employment, functional independence in daily activities, and total QOL, whilst overall satisfaction with life, integration with the community, and social belonging remained consistently low. Results demonstrated that four participants showed reliable improvement in QOL, four participants showed reliable deterioration, and one participant showed no reliable change. These findings also aligned with the categories of change in QOL utilised in the case series analysis. Thus, with respect to the first research question: *Does quality of life and key variables of social support and environmental contexts change over the 12-month transition period,* almost half of the participants showed an increase in QOL, whilst almost half of the participants showed a decrease in QOL. As a proxy, this indicates that almost half of the young adults showed a more successful transition, whilst almost half demonstrated significant difficulties, and experienced poor QOL at the second time-point. These findings support recent research that many individuals on the autism spectrum transitioning to adulthood have poor outcomes in independence, employment, post-secondary education, and experience overall poor social and psychological wellbeing (Wehman, Schall, Carr, et al., 2014). Thus, over time, individual change in QOL was noted during the transition period with approximately half the group showing a positive trend and approximately half showing a negative trend from baseline to follow-up.

In order to further examine the factors potentially associated with changes in QOL and to answer the second research question: *What factors are evident during the transition period that might be related to a successful or unsuccessful transition to adulthood,* a case series analysis of all participants was conducted. First, there were particular demographic and individual factors that appeared to be common among participants showing improvement and deterioration in QOL over the 12-month period. Specifically, for those participants demonstrating a positive increase in QOL and successful transition, common factors included engagement in post-secondary education, being in full-time employment, and having a partner. In addition, with respect to support and interventions previously received, exposure to work experience placements, support from a disability service provider, receipt of a transition plan, social skills training, life skills training, and behaviour support interventions at school, along with parental involvement in these interventions, were associated with positive change in QOL and successful transition. That is, those young adults who had received interventions in high school with a transition focus on educational and functional outcomes were also those who were able to successfully engage in post-secondary education and employment during the transition period. These findings are consistent with recent research which indicates with focused skills training and education in functional independence, access to work experience placements, as well as parental involvement, young adults on the autism spectrum can be successful in transitioning to post-secondary education and employment, and experience an improved QOL (Barnhill, 2016; Mitchell & Beresford, 2014; Pillay & Brownlow, 2017). Thus, the first hypothesis that further support will be found for the role of protective factors was partially supported, in that transition planning, support and intervention received at school, receipt of disability support services, and work experience placements appeared to facilitate a successful transition to post-secondary education and employment, and overall positive QOL.

Similar to those participants who showed some improvement in QOL, there were particular demographic and individual factors that appeared to be common among participants showing deterioration in QOL over the 12-month period. Specifically, a lack of engagement in post-secondary education, unemployment, and single status were common among participants who showed deterioration in QOL and unsuccessful transition over the follow-up period. In addition, with respect to support and interventions received, the absence of a transition plan, lack of disability service provider support, no social skills training, life skills training, or behaviour support intervention were common to these participants. That is, those young adults who did not receive interventions in high school, parental involvement, or support from a disability service provider, with no transition focus on educational and functional outcomes, were also those who were unable to successfully engage in post-secondary education and employment during the transition period. These findings are in agreement with recent research that early transition planning at high school with a multidimensional team including the young adult, family, and disability service provider, is crucial to facilitating a successful transition to post high school activities (Carter et al., 2014; Shattuck et al., 2012; Test et al., 2009). In particular, early access to work experience placements increased access to competitive paid employment, and specific post-secondary education goals improved post-secondary engagement (Test et al., 2009; Wehman, Schall, Carr, et al., 2014).

Second, although it was a proxy variable for successful transition, QOL itself appeared to act as a factor that may facilitate further improvement and successful transition. An increase in overall satisfaction with life, community integration, and social belonging as recorded by the QOLQ (Schalock & Keith, 1993) was associated with positive overall change. One case showed consistently high competence in employment over time, whilst improved competence and productivity in employment was associated in two cases that initially experienced difficulty in developing the skills and ability to feel productive in employment. However, over time, gaining part-time employment and earning a wage improved their overall satisfaction, feelings of being productive, functional independence, and social belonging, which may in turn have contributed to their overall successful transition. This supports previous research that being in competitive paid employment improved financial independence and social belonging, increased self-esteem, and led to success in adulthood (Gerhardt & Lainer, 2011; Lee & Carter, 2012; Roux et al., 2013).

Common across both groups experiencing successful or unsuccessful transition, and regardless of transition supports and interventions, co-occurring depression and anxiety emerged as risk factors to successful transition. A possible explanation for this finding is that for young adults on the autism spectrum with average to above average intellectual ability, anxiety occurs because these individuals are cognisant of their difficulty in social interactions, that depression occurs because of the stigma linked to coping with social difficulties, and collectively, that low self-esteem emerges because these individuals are aware of a combination of these difficulties (Attwood, 2008; Bellini, 2006; Ghaziuddin et al., 1998; Hillier et al., 2011; White et al., 2009).

Consistent with current research in the field, social and communication difficulties, and challenges in adaptive behaviour associated with ASD emerged as risk factors to a successful transition to post-secondary education, employment, independent living, and friendship formation (Bejerot et al., 2014; Higgins et al., 2008; VanBergeijk et al., 2008). Therefore, for young adults on the autism spectrum, the associated challenges of an ASD may make the transition to adult roles and responsibilities exceptionally difficult. Thus, the second hypothesis, that further support will be found for the role of risk factors was supported in that, lower functional independence, limited social skills, and communication challenges was evident across those who were less successful. Of note, these risk factors were also evident in some participants who were successful and showed improvement in QOL, but they appeared less impactful. One possible explanation is that the risk factors may have been buffered by other protective factors in this group experiencing successful transition.

Third, social support appeared crucial to participants demonstrating successful transition, although the nature of this differed for participants. For some, close relationships with families, especially mothers, were highlighted as important, as was the companionship of siblings. For others, the role of a significant other emerged as a key factor in providing functional support in daily living activities. These findings are in agreement with previous research by Robledo and Donnellan (2016) where qualitative interviews with academically successful adults on the autism spectrum identified two groups of supportive individuals, first, friends who provided support and, second, parents, and family members who provided support. Thus, support from friends, families, and significant others appeared to be protective factors for the group of young adults in the present study experiencing successful transition.

Similarly, for those participants showing unsuccessful transition, there were particular factors that appeared to be common to perceived social support, however, this varied based on individual choices of interaction and support. For two participants, lack of support from a significant other was a risk factor contributing to loneliness and isolation. Family support was important for one participant, whilst some chose to limit support from family and friends and did not appear to be distressed by this choice. These findings align with recent research by van Asselt-Goverts et al. (2015) in that some adults on the autism spectrum choose to have supportive friendships, however, they may be less important and less close when compared to neurotypical peers as in the case of Ms. Petal. Consistent with research by Plimley (2007) other individuals on the autism spectrum may have no desire to form friendships and prefer to live their lives with only a few social contacts, as in the case of Ms. Kylie. However, recent research indicates that those individuals who received support from family, friends, partners, and disability support workers experienced better overall physical and mental health, and improved QOL (Renty & Royers, 2006; van Asselt-Goverts et al., 2015). Thus, the perception of support from others varies for young adults on the autism spectrum based on individual preferences and choice.

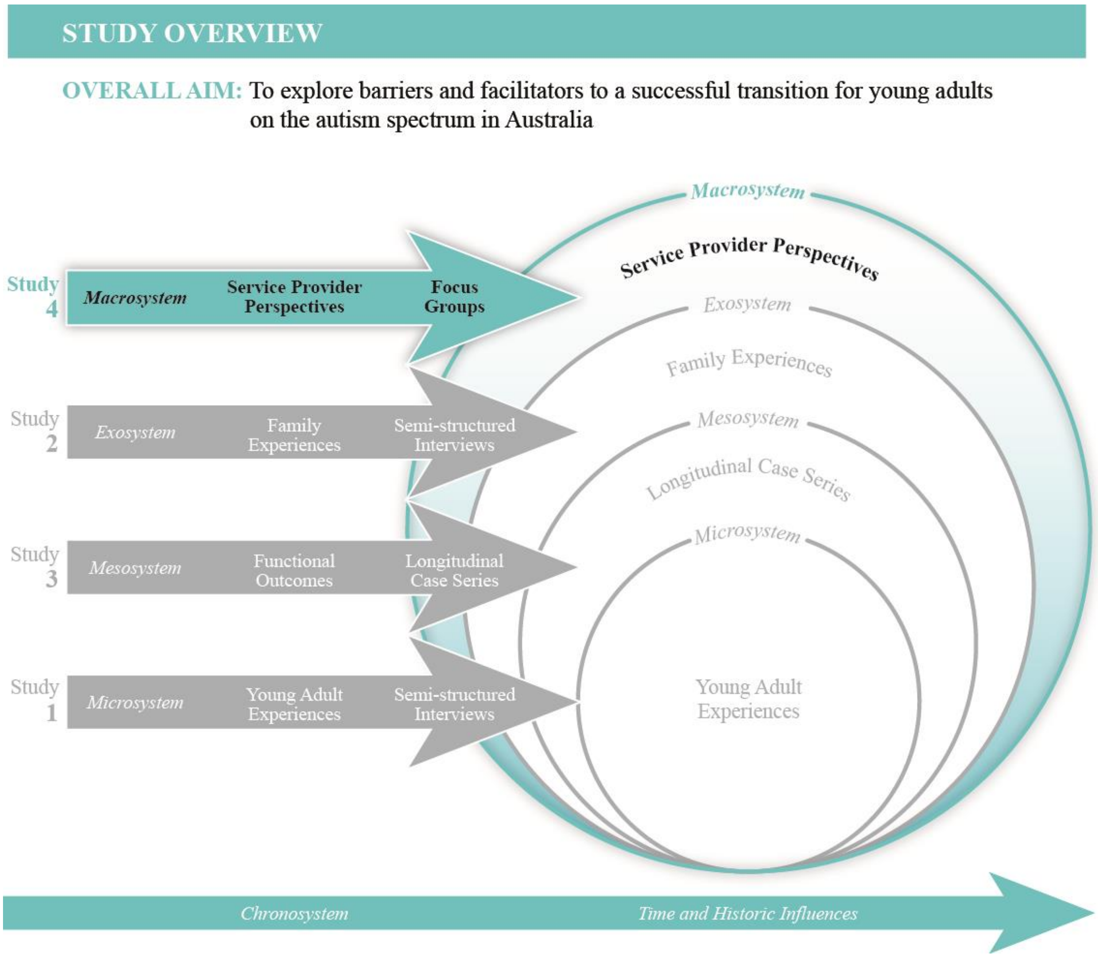
The hypothesis that further evidence for the role of family support as a protective factor was somewhat complex. Support from family was important to some degree across both groups experiencing successful and unsuccessful transition, and consistent with much of the research with families in the area of advocacy and support, family advocacy emerged as a protective factor in the group experiencing successful transition (see for example Barnhill, 2016; Mitchell & Beresford, 2014). On the contrary, interestingly and quite unexpectedly, parental advocacy was also perceived as a potential barrier in the group experiencing negative QOL. One possible explanation for this, is that the ongoing advocacy and support from parents is of benefit, and indeed necessary when supporting young children on the autism spectrum (Benson, 2012). However, parents of individuals with a disability can also be perceived as overly protective, likely due to a combination of a lack of both formal and informal support, and the perception that their young adult child is incapable to self-manage such changes as the transition to adulthood (Manos, 2009). As such, in the present study, the appearance of Mr. Reggie being a young adult attending post-secondary education and the associated social expectation of being independent, combined with having a parent advocate for him at enrolment, presented a confusing situation for staff untrained in ASD.

Fourth, the importance of the diagnosis of ASD appeared common amongst participants showing both successful and unsuccessful transition. Both cases that reported a late diagnosis of ASD and also experienced successful transition stated a sense of enlightenment in understanding their ASD differences that may have contributed to their positive changes in QOL over the follow-up period. Quite unexpectedly, most of the participants who experienced negative change in QOL and unsuccessful transition also reflected on how their ASD differences shaped their unique identities in a positive way. Although many struggled with anxiety and depression, communication, and social challenges, they embraced their ASD, and sought to increase ASD awareness by volunteering to support younger children on the autism spectrum understand their ASD differences. These findings concur with research by Müller et al. (2008) who reported participants in their study experienced an increase in social connectedness by contributing to the community through volunteering activities, and by participating in groups that shared a common interest, such as ASD support groups. Notably, there is a growing body of individuals on the autism spectrum giving voice to their experiences, self-awareness, and self-advocacy journey during the transition to adulthood (see for example Shore, 2003). Thus, it may be that in an effort to self-manage the impacts of their ASD during the crucial transition period, the young adults in the present study developed a sense of self-awareness, most likely as a potential protective factor in order to understand and navigate changes associated with adult roles and responsibilities.

Summary

This chapter presented the method, analysis, and findings from the longitudinal pilot case series study conducted in Study 3. The next chapter, Chapter 6, will explore service provider perspectives of successes and challenges in supporting young adults on the autism spectrum and families during the transition to adulthood.

Chapter 6 – Study 4: Service Provider Perspectives



STUDY OVERVIEW

OVERALL AIM: To explore barriers and facilitators to a successful transition for young adults on the autism spectrum in Australia

Figure 6.1. Flowchart summarising Study 4 service provider perspectives within the macrosystem.

Background

Within the Australian adult disability support infrastructure, a variety of formal government, not-for-profit, and private services are available to individuals with disability to provide assistance in meeting daily living requirements (Queensland Government, 2016). Two groups of service providers that support young adults between the ages of 18 to 25 years are Disability Service Providers (DSP) and Disability Employment Services (DES). First, DSP comprise of support workers and case managers that facilitate access to accommodation, community activities, respite, supported employment, self-advocacy, and volunteering activities for individuals with disability and their families (Queensland Government, 2016). Second, DES offer specialist services such as résumé development, job applications, and developing interview skills to job seekers with a disability who require support to find and maintain employment. Therefore, service providers are a critical link between young adults on the autism spectrum in facilitating access to adult roles and responsibilities such as independent living or employment, during the transition to adulthood. This chapter will explore service provider perspectives of successes and challenges in supporting young adults on the autism spectrum and families during the transition to adulthood. The present study strengths and limitations, implications of findings, and future research directions will be discussed in the general discussion in Chapter 7.

As discussed previously, given the increase in prevalence in ASD diagnosis the implication for the future is an influx of young adults on the autism spectrum with varying needs seeking adult support services. At present, the Australian disability infrastructure is undergoing reform with the implementation of the NDIS where four categories of eligibility for support are identified in cognitive, neurological, sensory, or a physical condition (Australian Department of Human Services, 2015). Within this general framework of eligibility, it remains unclear as to where young adults on the autism spectrum are positioned to seek and qualify for support. However, it is imperative that young adults on the autism spectrum receive the skills and services necessary to function independently in daily life activities, to access and maintain competitive paid employment, to be economically independent, and to learn how to integrate with others to be socially independent. Collectively, given the heterogeneity in adult outcomes for young adults on the autism spectrum, and narrow eligibility criteria within the NDIS, service providers need to be cognisant of the individual differences of young adults on the autism spectrum to ensure that both young adults and families experience a service response that is sensitive to their needs.

Bronfenbrenner's Ecological Systems Theory (1994) is well positioned to explore service provider interrelationships across disability policy, young adult, and family interactions. The macrosystem represents the larger cultural and societal context, beliefs, ideologies, policies, and laws that impact an individual. Within the context of the present study therefore, the macrosystem will be used as a framework to contribute an understanding of how service providers position young adults on the autism spectrum within the socio-political context of family, the environment, and Australian government systemic policy and practices.

Significance of the Present Study. Given the crucial role that service providers have in facilitating independent living, community access, supported access to employment, and family intervention, it is necessary to explore their perceptions of successes and challenges in post school activities for young adults on the autism spectrum and their families. The research question guiding this exploratory study was: *What are the successes and challenges during the transition to adulthood for young adults on the autism spectrum from the perspectives of service providers?*

Method

Qualitative methodology in the form of two face-to-face homogenous focus groups was used as a means of data collection. The first focus group comprised of Disability Support Providers (DSP) whilst the second focus group comprised of Disability Employment Services (DES). Support and services for young adults with a disability exiting high school are provided under the *Support for School Leavers* program (Disability Programs, 2017), a government initiative rolled over into the NDIS. Within this initiative, DSP and DES providers are two broad categories of support for individuals with disability, funded by the Australian government. Therefore, DSP and DES providers were chosen as a purposive sample as their perspectives are relevant to the young adult population within this thesis.

Focus groups were chosen as a platform to observe interactive group discussions amongst service providers who shared similar and different experiences in supporting young adults on the autism spectrum and families through the transition to adulthood. Engaging a small number of individuals in informal focus groups allows for the collection of data from multiple individuals simultaneously and also enables a richer picture to be established through observing the degree of consensus, dissent, and shared experiences between individuals. Utilising the group as a unit of analysis may present limited opportunity to hear the voices of those participants who may have differing opinions or for those who may be relatively quiet within group discussions. As such, it is suggested that individual perspectives are presented in the analysis to illustrate the views held by individual participants (Onwuegbuzie, Dickson, Leech, & Zoran, 2009). Therefore, through the voices of individual service providers, perceptions of successes and challenges of the transition experience were explored to provide a richer understanding of the transition phenomena of interest.

Recruitment

Ethics approval was granted from the University of Southern Queensland's Human Research Ethics Committee prior to recruitment (USQ: No. HI6REA141). Participants were recruited from the *Your Life Your Choice* service providers registered online with the Australian government Department of Communities and Disability Services (Queensland Government, 2012). This purposive sample was chosen as it allowed access to participants who support individuals with disability across Australia and are representative of a range of types of support, for example, access to community respite and leisure activities. Additionally, all service providers are registered with the Department of Communities, thereby ensuring services and supports meet the requirements of disability services policies. According to Marshall (1996) purposive sampling provides a rich understanding of the transition phenomena of interest. In addition, homogenous groups are preferred when participants have specialised knowledge and experiences to discuss in the group (Onwuegbuzie et al., 2009)

A letter of invitation including an information sheet about the study (Appendix I) was e-mailed to DSP and DES providers that work with autism spectrum populations. Individuals who read about the study via the information sheet and expressed their interest to the primary researcher were emailed a consent form (Appendix J). This form served to separate participants into one of two groups depending on how they identified themselves to the researcher, that is, as a DSP or a DES provider. The consent form also asked for participants to provide a pseudonym to the researcher to protect their identity during the focus group discussions and subsequent data analysis.

Each participant was sent a confirmation email with the suggested time and date of the one hour-long focus group, as well as a choice of venue. Both focus groups agreed upon a date, time, and venue, and each focus group was held on a separate day within a four-week period. The researcher facilitated the discussions throughout the course of the focus group, and also acted as a mediator between participants where appropriate. Focus group discussions were recorded on a Zoom H2 Handy recorder for the purpose of verbatim transcription and analysis.

Participants

Two separate participant pools were drawn upon for the current study. Each focus group comprised of seven participants with four males and three females in each group. Seven participants are considered an acceptable number in each focus group to be able to identify patterns and themes in the data when using thematic analysis (Braun & Clarke, 2013).

Focus Group 1 Disability Employment Services Providers (DES). Participants included program managers, case managers, and education specialists who provide workplace experience during high school and facilitate access to supported employment post high school for adolescents with disability. All DES providers are part of the Australian government funded employment support initiative for adults with a disability within the NDIS, and are presented in Table 6.1.

Table 6.1

Disability Employment Services Participant Demographics

Pseudonym	Gender	Age	Role	Type of Support	ASD Training	Experience
Nick	M	30-40	Manager	Access to employment	N	6 years
Kelly	F	30-40	Case worker	Access to employment	N	15 years
Marcus	M	50-60	Manager	Access to employment	N	10 years
Ben	M	30-40	Case Worker	Access to employment	N	9 years
Margie	F	50-60	Case Worker	Access to employment	N	4 years
Eddie	M	40-50	Case Worker	Access to employment	N	9 years
Sally	F	30-40	Case Worker	Access to employment	Y	10 years

Focus Group 2 Disability Service Providers (DSP). Participants in the DSP focus group included support workers who provide social-emotional support, community respite, access to independent accommodation, volunteer work experience placements, and self-advocacy initiatives to young adults on the autism spectrum, and are presented in Table 6.2.

Table 6.2

Disability Service Providers Participant Demographics

Pseudonym	Gender	Age	Role	Type of Support	ASD Training	Experience
Ann	F	30-40	Case Worker	Disability respite	Y	10 years
Jackie	F	30-40	Manager	Parent support	N	12 years
Rachel	F	30-40	Case Worker	Post-school options	N	5 years
Tess	F	30-40	Disability co-ordinator	Education	N	8 years
Pete	M	40-50	Case Worker	Respite	N	10 years
Lionel	M	40-50	Manager	Community activities	Y	12 years
Neal	M	50-60	Manager	Carer advocacy	N	20 years

Focus-Group Questions. Focus group questions were open-ended and explored perceptions of successes and challenges in the transition to adulthood for young adults on the autism spectrum as perceived by focus group participants (Appendix K). Discussion questions used within the current study were sourced from key areas of transition experiences as identified in Study 1, interviews with young adults on the autism spectrum, Study 2, interviews with parents of young adults on the autism spectrum, and Study 3 case series analysis. Questions were open-ended and used as precipitants for discussion with service providers. The specific questions developed for the focus groups were as follows:

- What are the specific challenges and successes working with and supporting young adults on the autism spectrum?

- What are your transition experiences with families of young adults on the autism spectrum?
- What are the strengths and weaknesses within the model of service provision?

Data Trustworthiness

In order to strengthen the data collection process, analysis, and trustworthiness, there were a number of methodological actions implemented. These included researcher reflexivity as discussed in Chapter 1, evaluation, comparison and regular discussion of coding with research supervisors, and initial service provider member checks (Lincoln & Guba, 1985). The researcher and both supervisors independently reviewed transcripts to ensure agreement on thematic elements. Based on the initial coding, transcripts were reviewed several times and were subjected to six months of intensive coding and refinement. Two focus group participants engaged in a second round of member checking of focus group transcripts. Both participants agreed on the information in the transcripts with one participant adding more detail.

Data Analysis

Thematic analysis informed by Braun and Clarke (2006) was used to analyse the focus group data. An inductive approach to analysis identified themes and patterns across participants' shared experiences as well as individual perceptions of the transition phenomena of interest. Identified themes captured information relative to the research question: *What are the successes and challenges during the transition to adulthood for young adults on the autism spectrum from the perspectives of service providers?* In addition, the broader implications and meanings of themes were interpreted. In this way, the sociocultural context and structural conditions that underpin service provider recounts of transition challenges and successes were explored in detail.

Following Braun and Clarke’s (2006) six steps of data analysis, participants’ responses were transcribed verbatim. The first step was to become familiar with the data through reading and re-reading participant responses and writing notes on the transcript about key ideas relevant to the research question. During the second step of analysis, initial codes were generated to assist with organising the data into meaningful categories of information. For example, focus group questions explored participant experiences with families of young adults on the autism spectrum. Therefore, when coding a participant’s response, an initial main theme was given, for example, *Collaborative Relationships*, followed by subsequent subthemes, for example, *Family Expectations of Service Providers*. During this second stage of analysis, research supervisors independently annotated initial codes on the focus group transcripts in order to aid analytical rigour. Regular discussion about coding and any discrepancies informed the development of an initial matrix of codes.

The third step involved collating the coded data into potential themes and sub themes using a visual thematic map. An example of this coding process is firstly identifying a main theme such as, *Relationships*, then embedding subsequent sub-themes, such as, *Family Challenges*, within this main theme of *Relationships*. Together, the themes and sub themes informed the overall story of transition experiences, challenges, and successes of both young adults on the autism spectrum and their families, from the perspectives of service providers.

During the fourth step, subthemes were reviewed and refined against each main theme to ensure a best fit and form a coherent pattern (Braun & Clark, 2012). Similarities and differences in themes within and across focus groups were identified by organising direct quotations in columns of themes and rows of focus groups. At this point three broad themes emerged relative to transition experiences within an ecological system: (1) collaborative relationships, (2) ASD specific challenges, and (3) organisational influences. During the fifth step, themes were further refined and named so as to articulate the essence of the overall transition story. For example, the main theme of *Organisational Influences* captures important contextual information within a service provider systems perspective. However, *Organisational Influences* also accurately reflects the meaning of the subtheme, *Interactions with the School System*. At this stage of the analysis, main themes and subthemes were presented to one service provider with the intent of transparency and member checking in the analysis process (Yardley, 2000). Further detail was added to aid with clarity in the interpretation and this was incorporated in the final write up. The sixth step involved writing up the analysis presented below. Care was taken to distinguish between shared and individual perceptions to capture the richness of the data (Onwuegbuzie et al., 2009). As such, direct quotations and analysis presented in the next section, includes both individual focus group participants experience, as well as shared experiences across focus groups.

Findings

Thematic analysis identified one overarching dominant narrative within both the DSP and DES provider focus group discussions, which is, that service provision occurs and is influenced by different facets within a socio-cultural and socio-political context. The main themes of *ASD Specific challenges* and *Organisational Influences* emerged as key links between the dominant socio-political and cultural context. In addition, a third main theme of *Collaborative relationships* was also identified. Each main theme was further broken down into subthemes as indicated in Table 6.3 below.

Table 6.3

Shared Themes Emerging from Thematic Analysis of Interviews with Service Providers

Theme 1	Collaborative Relationships • Family Challenges • Family Expectation of Service Providers
Theme 2	ASD Specific Challenges • Service Provider Understanding of ASD • Employer Understanding of ASD
Theme 3	Organisational Influences • Interaction with the School System • Service Provider Infrastructure

Theme 1: Collaborative Relationships

Participants discussed the importance of open and direct communication in developing and sustaining productive partnerships with families, schools, and employers. Within this main theme service providers drew upon their interactions with families of young adults on the autism spectrum to discuss family expectations of support services.

Family Challenges

Some challenges that parents typically faced, as identified by service providers, included difficulty linking their young adult children to an appropriate service provider, the result being a lack of support in a specific area of need. For example, Jackie (DSP) raised a concern that if a service provider felt threatened or in danger by emotional outbursts in young adults, support provision was withdrawn. As a result, parents are left to manage challenging behaviour without formal intervention. In Jackie's words the impact on such parents included "*depression and anxiety*"

(Jackie, 16). Further, as young adults explore independence in adulthood, parents may continue to feel anxious.

In Jackie's (DSP) experience, as young adults on the autism spectrum make decisions about future living arrangements, they may be influenced by what their peers are currently doing:

> Also moving out of home, and moving into a college and stuff like that, some of these young people have been found to be led astray by other adults in the community, almost being brainwashed out of living with their families because they're so gullible, and parents don't have much support or say because these children are over 18, legally they're adults (Jackie, 26-32).

Even though young adults on the autism spectrum may not have the necessary skills to live independently, through Jackie's lens, parents experience a tug-of-war between young adults being of the legal age of 18 to live independently, and their role of a parent as caregiver to ensure the safety and wellbeing of their children. As such, this presents a challenge for parents:

> Even though you're their carer it's really hard to be, there's that internal backing in the home where you can support them, when's the right time to let go? That's some of the big issues, that, how do we change our caring role from parent to carer but supporting them to grow up, and there's not much information out there on how to do that (Jackie, 32-36).

Here Jackie presents the quandary that many parents of young adults on the autism spectrum face when confronting responsibilities associated with adulthood, and "*letting go*" of their young adult child who may have difficulty in dealing with daily life experiences. In her quote above, it would seem that there is limited information, interaction, and communication with services on how to support their adult children.

Ben (DES) extends on Jackie's comments as he is faced with limited housing resources in response to some parents concerns of independent living:

> Some parents would like the kids to live independently, and that's a massive transition as well, on top of finding a job, getting used to the system and

> finding a place for themselves or a house share, they need social skills or even independent skills and that can be tricky. There is no transition housing for them to just live into a house share, and that is a massive stressor (Ben, 489-495).

In this context Ben lists the adaptive skills required to live independently from his perspective. Specifically, social skills emerge as an important factor to be able to share accommodation with other people. Additionally, independence in daily living skills emerges as another important factor to be able to manage living in shared accommodation. Within a holistic context, Ben provides examples of some adult responsibilities that may occur simultaneously. For example, finding a job is perceived as an important adult responsibility. Moreover, Ben draws attention to navigating the disability support system in accessing appropriate support services. It is known that managing change of routine, such as looking for employment, and adapting to new situations, such as sharing accommodation, can be challenging for individuals on the autism spectrum and disrupt daily functioning (Taylor & Mailick, 2014). Additionally, in Ben's view it seems as though service provision and transition support to independent living is non-existent for young adults with disability.

In a different vein, Rachel (DSP) provides the example of a family who experiences a poor QOL because of their young adult son's issues with hoarding, poor hygiene, and a lack of social awareness. In this example, the situation appears to have a double-edged sword:

> He never had those supports in place with his family, no professional supports to help him through his schooling, so he dropped out of school. He continued to live with his parents, and it was his fault that his parents didn't have a good quality of family life. His parents expect him to do this, and that, and get into business management. Actually he's just falling apart (Rachel, 44-52).

On the one hand, it seems as though the family is experiencing poor QOL because of their young adult son's challenging behaviour. On the other hand, it is unclear as to whether the family communicated with support services or the school system to seek disability support for their son whilst at school. It might be the case that had this young adult received support at school the situation may not have reached such dire straits. In addition, it would appear that the parents have high expectations and are demanding of their young adult. Consequently, both the family and the young adult are experiencing a poor QOL.

Family Expectation of Service Providers

Service providers spoke about expectations of families as they endeavoured to find employment that matched young adults' interests, abilities, and skill sets. There appeared to be an underlying tension between work experiences recommended by service providers, with some parents demanding work options beyond the scope of the ability of the young adult. This tension was consistent in all DES provider experiences as they expressed their frustration as can bee seen in both Nick (DES) and Ben's (DES) experience:

> I had a kid that I worked with. He was very specific. We got him a job in an electronics company, and his mum decided it was the wrong job. She wanted us to find him more the robotic side of it. Just trying to explain to her that those jobs are not available to a kid who has no experience, the kid was actually fine, for me it was keeping him in a realistic job. I have to say in trying to keep them in employment it's usually the parents that are an issue for us (Nick, 7-21).

Nick alludes to the young adult's interest in electronics, and accordingly matched this interest with a work placement in an electronics company. However, in this instance it would seem that the mother's perception of a more challenging job in robotics placed undue pressure and expectation on the service provider to find such a work placement. In addition, the young adult appeared to enjoy the present work placement in electronics, and a change to a work placement in robotics that is more challenging might be difficult for the young adult to adjust to. Similarly, Ben echoes

Nick's experience and highlights the tension that arises from the pressure placed on the service provider:

> Parents are the primary carers, and actually they were asking us in some ways to relieve the pressure from them, by trying to change the children's reaction, and putting a lot of pressure on us, and interfering with the relationship. Once the parent is gone, the child is like, no that's not what I want to do, and we find that kind of conflicting relationship quite stressful for the young adult trying to get work (Ben, 36-44).

Communication between service providers, parents, and the young adult is recognised as an important factor in facilitating support and intervention. However, in Ben's perspective parental pressure impacts the relationship with potentially negative consequences. It would appear that parental pressure is extended to some parents placing high expectations on their young adult child. It might be the case that this parental expectation is above the ability level or out of the scope of interest of their young adult child. Indeed, such high parent expectation can lead to low work satisfaction and unhappiness for the young adult.

On a different note, Rachel (DSP) refers to a lack of family understanding of how support is provided. She refers to communication difficulties experienced when interacting with some parents:

> A lot of the people that we support in that age group, their parents are quite often on the spectrum, so there's that link breakdown again, because that communication drops quick and you can't share that information in a way you maybe need to (Rachel, 151-161).

Here Rachel mentions a breakdown in communication between service providers and families impacting sharing information potentially of how service provision functions. It might be that in Rachel's experience, parents themselves are experiencing communication difficulties. Combined with a lack of understanding of how support is provided to families, she notes this misunderstanding below:

> Another one is a lot of them have not had support services, so when we do start going into the home and providing those services, there's a real issue

> with it, because they’re not used to it, so we end up supporting mum and dad (Rachel, 161-162).

It would seem that many families have not previously received support services for their young adult. As such, when service providers meet with families to discuss support needs for the young adult, it is often the case that parents themselves require and expect social-emotional and/or financial support. This expectation then places increased demand on service providers impacting stress and strain on the relationship. This experience is shared across both focus groups, as Kelly (DES) extends on this theme by iterating her experience below:

> Sometimes the expectation doesn’t actually match what the parent expectation of the provider is, so I suppose…not only do we have to find somewhere where they feel comfortable we also have to find an employer and a work place where it is supportive for that young person as well, and sometimes the expectations from the family or parent that is put onto the provider is a little bit difficult (Kelly, 22-28).

In her recount above, Kelly expands on the groundwork required in matching the young adult’s interest with a suitable work placement, finding a supportive workplace, and fulfilling parent expectations. The process requires a network of planning and appears time consuming. Whilst she succinctly presents the DES provider role and positions the needs of the young adult as a priority, there is an underlying tension of undue parental pressure and expectation on service providers.

Summary

In summary, it would appear that many families lacked knowledge about available support services or how to access them. As a result, the young adult child either received no support, or received support that did not match their specific need. The ramifications of limited parental knowledge therefore, were high expectations of service providers, increased demand on the young adult sometimes above their ability level, and parental interference with the formal support provider intervention process.

Theme 2: ASD Specific Challenges

Of the fourteen service providers who contributed to the focus groups, only two providers had accessed professional development and training in ASD during the course of their employment as service providers. Despite the lack of formal training in understanding ASD, many service providers acknowledged the pros and cons of ASD specific fixations and interests specifically with regards to employment, managing difficult behaviours, and communicating ASD challenges with potential employers. However, some service providers alluded to underlying tensions in employer expectation.

Service Provider Experience of ASD

All service providers acknowledged the intricacies of supporting young adults on the autism spectrum. For example, Jackie (DSP) raised a concern when interacting with young adults on the autism spectrum that some service providers may not be educated in understanding ASD and therefore may be unaware of how to identify and manage specific behaviours. Consequently, young adults on the autism spectrum are perceived as violent and unstable:

> That was one of the big problems that was fed back to me from parents, was behaviours were difficult to manage, service providers were reluctant to help with support, because (a) they didn't want to put their workers in danger, and (b) the young person was simply too hard, even though that parent desperately needed that help, that child was put in the too hard basket (Jackie, 11-15).

It seems as though challenging behaviour associated with ASD are aligned with intentional violence by young adults on the autism spectrum towards support workers. The impact of such misinterpretation leaves parents fraught with anxiety with a loss of formal support. Pete (DES) expands on Jackie's concerns and highlights the challenge of recruiting staff trained to work with young adults on the autism spectrum, specifically to manage difficult behaviours and facilitate communication in work experience placement:

> We don’t have the staff or the support, in other words if we have kids with high needs, with behaviour issues we can’t really deal with, we don’t have the staff (Pete, 87-89).

Here Pete’s comment reflects a continuous cyclical pattern of events. On the one hand, there is a shortage of staff trained to work with young adults on the autism spectrum. On the other hand, it might be the case that there is insufficient training provided to current staff in supporting young adults on the autism spectrum. Service providers shared a common concern of a lack of experienced support workers to manage young adults on the autism spectrum.

Some service providers, positioned young adults on the autism spectrum within an abilities perspective, while for other service providers, there appeared to be an underlying tension in some of their reflections. For example, in Pete’s (DSP) experience:

> The difference is with some people with that age on the spectrum, there’s noise, their social skills, lots of things that are damaging to them, but they also carry some incredible traits, positive traits, like they will apply themselves and they will continue with something, it differs from person to person, you can’t generalise (Pete, 74-77).

Here Pete acknowledges the difficulties associated with ASD. However, he also alludes to the positive attributes. Jackie (DSP) echoes Pete’s perspective and illuminates the positive aspects of ASD through an ability lens:

> He’s the kind of guy who will get fixated on something and will get the job done until it’s done. Yes, he’s a little bit slower on the computer than most of the other guys, but if he’s got a task he can do, he does it exceptionally well (Jackie, 120-124).

She continues to expand on this metaphor from an abilities perspective:

> It’s about finding these people their niche in the world, instead of making them feel that, woe me I can’t do anything. It’s not about what you can’t do, but what you can do and how well you can do that job (Jackie, 121-126).

Here Jackie (DSP) demonstrates an understanding in matching the needs of the young adult with their abilities, as she crafts a positive approach to supporting young adults on the autism spectrum. She also alludes to harnessing individual fixations and interests and using them to engage young adults on the autism spectrum productively in the workplace.

On a different note, Mark (DES) acknowledges individual differences in young adults on the autism spectrum just as Pete does. However, there is an underlying tension as he speaks of the intense effort required to facilitate support. As Mark lists the different steps involved in facilitating support, it is almost as though each step is a hurdle with the hope that the end will result in employment for the young adult. For all of the effort required, in Mark's experience, the outcome in finding suitable employment for the young adult may only be small:

> Because these people have got unique barriers, it's a challenge even just trying to engage with them, let alone get them to that stage where they're work ready, or find that ideal job. You've got to do a lot of prep work (Mark, 123-129).

Jackie recognises this tension in Mark's comment and draws on his reference to the amount of effort needed to make some progress in achieving employment. Her response is almost plea with a sense of urgency in her voice. In Jackie's iteration, she reveals a personal insight that is a reflection potentially of service provider health and wellbeing:

> And I guess the only thing you can do in that situation, and you can't stop the train wreck, you yourself putting yourself in emotional distress doing it. And as service providers everyone, we need to ask ourselves that question, are we going to put ourselves in danger, that position mentally or physically to put that support in place (Jackie, 224-253).

In a different vein, Ben's (DES) experience of supporting young adults on the autism spectrum with a co-existing ID was somewhat different:

> With the people over 16 but with mental health as their primary disability, there has to be comorbidity. Once we work with them on the mental health stuff and we see that this person also needs support for autism, but the support is mainly for mental health issues as their primary disability (Ben, 285-288).

It would seem that there is more of a focus on mental health needs in the young adults that Ben supports, and, as such, ASD is considered a secondary difficulty. Two thoughts emerge from Ben’s experience. First, service provision is targeted at young adults with mental health and wellbeing difficulties, therefore, if young adults on the autism spectrum present with co-occurring mental health difficulties they will receive support. Second, it is unclear then, if service providers at Ben’s support facility are trained to support young adults on the autism spectrum, even though their ASD is positioned as a secondary concern.

Employer Understanding of ASD

Through service provider voices, it would seem that a key factor driving employer understanding of ASD is based on negative connotations of *deficit*s in abilities and perceived limited work capacity of young adults on the autism spectrum. As such, if support in the workplace is required, this is perceived as an increased cost factor through the employer’s lens. In addition, limited work capacity and reduced productivity imply less of a profit margin to the employer. The common thread here it would seem is underpinned by the cost-benefit factor to the employer.

Some service providers mentioned community perceptions of ASD influencing accessibility to employment for young adults:

> We don’t do the ASD when we’re talking to employers, large employers aren’t really interested, its costs them more to administer it than it’s worth. They just say no we’re not interested, but it’s surprising because you think looking from an employer’s point of view it would be easier for a large organisation to accommodate someone, than someone with a small business (Kelly, 173-177).

In Kelly's experience, employers are reluctant to accept young adults on the autism spectrum possibly because they require support, which equates to an added expense factor. In a similar context, Rachel (DSP) reports trying to actively address this issue with employers:

> It's getting employers to understand, and be open and accepting of ASD, because a lot of it is, oh no I can place someone the same way as you, and the job gets done, because you don't quite understand how it's done, the job doesn't get done, or done quite as quickly, and it's costing the employers money. You either get it or you don't, and the employers are very cut throat like that, it's all about the dollar and there's no compassion for anyone (Rachel, 66-74).

The passion in Rachel's (DSP) voice is robust as she advocates for the needs of the young adults on the autism spectrum that she supports and for recognition of their abilities. However, it would seem that employers perceive young adults on the autism spectrum as compromised with limited productivity in the workplace, and, based on this premise, young adults appear to be excluded from the workforce.

Similarly, Neal (DSP) echoes both Rachel (DSP) and Kelly's (DES) narrative above as he articulates this viewpoint:

> They've all got policies in place, saying yes, we will support. What happens is hugely individuals are held to able-bodied criteria, and so you set yourself for failure straight up…They get blinkers on themselves, and they are looking from a rational perspective and they're looking at that person as an irrational individual with narrow opportunities and flexibilities (Neal, 186-192).

Neal's (DSP) tone appears monotonous as he comments on the potential contradictory behaviour of employers. Within a systemic level, Neal alludes to the underlying employer appearance of being supportive of young adults with disability by following institutional workplace policy. However, the behaviour of such employers in precluding individuals on the autism spectrum from the workplace demonstrates a naïve and discriminatory perception, reinforced through phrases such as "*able-bodied*" and "*irrational.*"

Ed (DES) builds on Neal's (DSP) narrative and expands on some skills required in the workplace:

> A lot of employers nowadays want people to multitask…You know if a truck comes in they call the manager for staff, if there's loads of people in the store they all go on the tills, and that's where it becomes a real problem, trying to say to them, we've got this person who can only do this and this, and they're saying well we want someone who can do a lot of different things, and a lot of employers are like that now (Ed, 122-128).

In this reflection, Ed (DES) highlights the ability to multitask as a key requirement with many employers. Within this context of multitasking, restrictive and repetitive patterns of behaviour associated with ASD and young adults on the autism spectrum, present a potential barrier to employment. Nevertheless, Ed (DES) is emphatic on the importance of understanding individual skills set and matching the type of employment to their abilities:

> These people have got barriers, they've got challenges, they've got issues, so you've got to first of all understand the individual, then you've got to go out and find what things float their boat, what industries might match those skills, then you have to go out and pound the pathways and build relationships and that's the only way it happens (Ed, 252-255).

Here Ed (DES) builds a case that it is the communication and relationship between the service provider and the employer that is crucial to accessing employment opportunities for young adults on the autism spectrum. Ed (DES) appears persistent in his tone with a sense of urgency about understanding individual needs, conveying these to employers, and matching the young adult on the autism spectrum with suitable employment.

Margie (DES) shares Ed's (DES) thoughts as she raises the importance of educating employers about the positive contributions of young adults on the autism spectrum. Here she mentions:

> I think there's certainly a need for more training, for staff working in those areas and with the employers, educating them for what to expect, you don't always see the behaviour, they will be fine for a while, and when they're not,

> then what pressures and challenges they might be under, so I think education is important (Margie, 96-99).

Here Margie acknowledges the importance of educating both employers and co-workers on the individual needs of young adults on the autism spectrum. In the workplace, there may be work related tasks, understanding instructions, and social interactions that may present challenges for young adults on the autism spectrum. In Margie's experience, employers and staff would benefit by gaining an understanding of individual needs. In a different vein, Pete (DSP) demonstrates the role of special interests and routine in the workplace:

> You know, champagne children, and issues at home. We have one boy, he's 18, he loves doing this delivering water job, he absolutely loves it, and if that job isn't available for him, apparently, he loses it at home. We don't see any of that at work, at work all we see is him being happy, he gets home and his mom tells me, you know, there's big issues (Pete, 91-95).

Here Pete (DSP) recognises the importance of maintaining a routine in work placements and highlights the impact if that routine is suddenly interrupted. His reference to "*champagne"* conjures visions of explosions and potential mayhem, unknown to him as a service provider as this meltdown in enacted at home. In light of this scenario, Pete (DSP) emphasises the need for regular communication between service providers and families of young adults on the autism spectrum.

Summary

In summary, service providers struggled between advocating for young adults to access employment and addressing community misperceptions of ASD. All service providers perceived ASD within an abilities lens, but acknowledged funding limitations in facilitating appropriate workplace support. Many service providers demonstrated an understanding of matching individual interests with employment type, but acknowledged that limited understanding of ASD may present a barrier to effective service provision. Shortage of trained staff emerged as a key factor impacting support in managing ASD specific behaviours. Collectively, effective service provision appeared to be hampered by a combination of employer awareness of ASD, and imposed elements of funding associated with organisational infrastructure.

Theme 3: Organisational influences

An underlying tension across subthemes alluded to systemic influences of government funding, meeting performance outcomes, and impacts on the quality of service provision. A large part of focus group discussions centred on coordinating the institutional complexities that involved transitioning young adults from the school system to the adult service system. These determinants included interaction with schools, discussions with employers, and the service provider operational infrastructure. Additionally, all service providers spoke about the demands in meeting targeted performance indicators to secure future government funding as well as ensuring both young adult and employer satisfaction in the workplace.

Interaction with the School System

Service providers referred to unmet needs in service provision to students at the school level due to changes in how DES providers are allowed to access students with a disability. Within a previous service model, DES providers were funded and allowed to support students with disability in high school from year 10 through to year 12. At present, the current model has been revised so that DES providers support to high school students with a disability in a reduced time of the last six months of year 12. In their experience, all DES providers acknowledged that six months was too short a time frame to build the necessary skills required to seek and gain employment:

> We used to be able to work with students in year 10 and 11…I found that when we were able to do that we had a bit more time, when they were a little

> bit younger, and it would prepare them a little bit better for when they were actually ready for work (Kelly, 62-66).

Here Kelly refers to preparing students on the autism spectrum for employment, which is a key role of DES providers. Kelly highlights the importance of developing work-related skills over time to facilitate a move into employment with some degree of ease:

> I would work at the schools and I would take them in a group how to hand out resumes, and we would go and get interview clothes, stuff like that, it was actually preparing them for work and at the end of that I would find them work. You know if I started working with them in grade 11 by year 12 most of them, had a part time job or work experience for one day a week, but that's gone (Kelly, 474-477).

Here, the short time frame of six months and the quick shift between school and work experience within a week, is highlighted as having an impact on how students on the autism spectrum cope with these changing roles and requirements. Moreover, Nick mentions the relational dimension of the partnership between the student on the autism spectrum and the DES provider:

> Introducing them to someone they haven't met before, a new person, and expecting them to be job ready in a few weeks, a month, or two months, it's like a massive change to their routine, and then keeping them in work when you change their whole school schedule and work schedule, it's a lot of change, it's a real challenge (Nick, 73-77).

Here Nick refers to difficulties that individuals' on the autism spectrum experience in interacting with unfamiliar people. For example, having a DES provider work with the student once a week requires a relationship built on effective communication and understanding. It is likely that the six-month allocated period is too short a timeframe to build an effective working relationship. As is known, communication and social interaction is an area of difficulty for individuals on the autism spectrum, and could therefore take a long time for students on the autism spectrum to develop a meaningful relationship with the DES provider. Additionally, a sudden change in routine from attending school for five days a week, to attending school for four days a week to incorporate a one-day a week work placement could escalate student anxiety levels.

Within a systems perspective, Mark (DSP) highlighted:

> From the government point of view, it's about ticking the boxes, and statistical data for the public…but by rushing it all, into a smaller time frame in moving them on, is not going to help these children at all. That level of contact required for all intents and purposes, it needs to be very intense, you've got to build those trust factors (Mark, 84-89).

Mark (DSP) echoes both Kelly (DES) and Nick's (DES) concerns in building relationships over time with students on the autism spectrum; however, it would seem that service providers are bound by the constraints of policy and legislative requirements. From a systems perspective Nick (DES) extrapolates on policy implementation and requirements to receive DES provider support at the school level:

> The students who actually qualify for employment services, the school has to receive some type of funding for them for their disability, so the ones that we support are more obviously on the spectrum, but there's a lot of families with kids on the spectrum who are not linked up with funding (Nick, 280-284).

In Nick's (DES) experience, many students at the school level require DES support, but are ineligible, as they do not have a formal diagnosis of ASD:

> I got asked to sign a bunch of kids up at a school, and when I turn up for these 5 students, to register them, there's about 22 kids in the class and I was there to do a couple of hours on how to get a job and they wanted us to be there every week (Nick, 459-462).

Here Nick (DES) alludes to the limitations in DES provider funding here allocated specifically to support students with an ASD diagnosis. Ed (DES) builds on Nick's experience and contributes his perception:

> Cause we're only paid if they're actually linked to us, if we go into a school, and do a group program like you were asked to do, you can do it from the kindness of your heart, but at the end you just make a rod for your own back (Ed, 466-469).

Ed’s (DES) response here echoes Nick’s (DES) iteration of a high need in schools to support an increasing number of students on the autism spectrum. However, there is also a tension in this narrative between demonstrating compassionate support for ineligible students and funding limitations.

Within a broader context, Sally (DES) highlights the long-term ramifications for such ineligible students:

> If they don’t get captured during the school period, they will get lost in the main system, because they don’t have a very obvious disability, these kids usually go into a needs assessment, won’t get assessed with a disability and won’t be told you need to go to DES (Sally, 424-428).

Here the reality of future loss of support in adulthood is brought to the fore as access to disability funding, employment support, and respite hinge on an ASD diagnosis and subsequent support at the school level.

In a different vein, Sally (DES) sees the school’s role in taking the lead as crucial. She highlights some important factors in supporting students with ASD at the school level. These include an individualised transition plan, targeted goal of work experience placement, and access to the work environment. It would seem that the schools that Sally facilitates support at demonstrate an in-depth understanding of ASD and implement strategic planning and resourcing accordingly:

> Certain schools I work with they have a much better understanding of what these kids need. They actually develop a tailored personalised transition plan for those ASD kids and they put them into a work experience program, introduce them to the work environment to the business out there (Sally, 413-414).

It would seem that such schools are proactive and support students on the autism spectrum to access work experience early:

> Some of the schools have the resources, they have the transition specialist teachers, they have the work experience program teacher to come into place to help those kids, but if they don’t get captured in that period of time, they can get easily lost in the system (Sally, 445-448).

However, it also seems that such schools prioritise resources to individuals on the autism spectrum. In this way, Sally (DES) sees this proactive behaviour as a win-win situation:

> Businesses then have an understanding, they have a chance to see them, how they actually interact in the work place. The boss will have an understanding of how these kids progress over the period of the work experience program (Sally, 415-416).

Through her lens, Sally (DES) sees crafting early work experience as beneficial in introducing students on the autism spectrum to the workplace, as well as providing the employer with an opportunity to observe students work ability. It might be the case that access to work experience programs earlier (in year 10) rather than later (in the last six months of high school), may facilitate transition to employment with some ease after high school and avoid stereotypical employer misperceptions of ASD.

Service Provider Infrastructure

The contributing factors underpinning effective support largely pointed to policy implementation, funding, meeting performance indicators, and institutional relations between government and community service providers. Some service providers grappled with striking a balance between meeting organisational expectations and supporting individuals on the autism spectrum, usually perceived as difficult clients. Here Kelly (DES) outlines the process of how funding is allocated:

> Our outcomes are basically driven from the government expectations, so our clients have to meet their benchmark hours. So, if we get a client for 15 hours a week, we have to find work for that 15 hours a week, so how we get our funding, is when we get to 13 weeks of employment, and that’s how we run, that’s how we get staff, that’s how we pay our lease, it’s from our funding from our outcomes (Kelly, 258-266).

Here, Kelly (DES) articulates the link between funding and successful work placement of their young adults as measured in hours. Neal (DSP) builds on Kelly's (DES) narrative from a management perspective:

> We have expectations on us, because we have to pay the bills, the lights have to come on and that sort of stuff, the government judges us equally. So, we have our star ratings, and, we all pride ourselves on how well we do, and they're all external pressures and in the middle of this we're working with people who really don't fit, we're trying to put a square peg into a round hole (Neal, 255-260).

Here Neal (DSP) presents a picture of the performance demands on service providers from an organisational perspective. In his articulation, he demonstrates the difficulty of managing challenging young adults on the autism spectrum whose successes or failures are reflected in organisational performance outcomes. Ed (DES) echoes Neal's (DSP) perspective:

> It comes back to that rational workplace scenario being placed on them. It seems to be the flavour of the month with all government organisations'. They try and make one size fit all (Ed, 121-129).

A common thread here in both Neal (DSP) and Ed's (DES) narrative is the ignorance of government understandings of the complexities in managing young adults on the autism spectrum. In their iterations above, within a systems perspective, organisational demands and performance indicators are prioritised over the needs of young adults on the autism spectrum. Further, Ed (DES) highlights the onerous process required to facilitate access to employment:

> What we work on is really about job creation for these clients, which takes time. It really does, coming back to expectations from the family, outside support networks. It's not realistic for us to have just a few appointments with that person, and then have them something. It literally means we have to create a job within a business for that person (Ed, 154-158).

As such, service providers appear overwhelmed between meeting performance outcomes and providing support for young adults on the autism spectrum, which in their perspectives is demanding and not always successful. This idea is echoed emphatically across focus group participants. As Mark (DES) mentions below:

> The other side is that we are a working in a reality where we put a number value for an outcome…KPI's all that sort of stuff, but it's very hard trying to get an individual to conform to that rationale when they have their own needs, their own wants, they see the world in a totally different way. Where do we build that bridge, that overall understanding, that empathy to allow us to give that support that we need to give, without having that pressure from management (Mark, 235-230).

As Mark (DES) echoes both Neal (DSP) and Ed's (DES) experiences, an underlying tone of compassion and empathy emerges in his narrative above. However, in a reflective moment, Ed (DES) points to reality:

> Because we're driven down the outcomes based, performance based, as you get people come onto your case load, you're going to look for the easiest people to place. You're not going to want to work with the people down the bottom. You're going to have to have to do a lot of work with them. They just sit at the bottom, swimming around (Ed, 309-315).

Given the expectation placed on performance indicators, it may be the case that since young adults on the autism spectrum are difficult and require extensive planning to place in employment, they are moved to the bottom of the service provider list, whilst other supposedly "*easier*" individuals with disability are supported to access employment.

In a different context, Ann (DSP) alludes to funding and specifically highlighted the high employment turnover in support workers, and the impact this has on developing and maintaining a relationship with families in facilitating support:

> One thing that people consistently say is that it's too hard. If you're trying to support someone in shifts and they find it hard to find services that will stick with them, that consistency so that you get the same workers that will support that person properly and get to know that person properly. I guess having the funding so that one person works consistently with that young person is a real issue (Ann, 2-10).

Ann (DSP) refers to the challenges experienced by service providers in building a long-term relationship with the young adult and families. It would appear that shift work is demanding, rotational, and does not provide consistency in maintaining a routine with the same service provider supporting the same young adult regularly. It would seem that limited funding also plays a role in maintaining consistency in staff.

Summary

In summary, focus group participants highlighted both the challenges of working within restricted time frames in transition support for young adults at the school level, and successes of some schools, in effective early transition organisation and planning. Issues with consistency of staff recruitment, training and retention, and systemic organisational markers of meeting key performance outcomes, presented challenges to effective service provision. All focus group participants emphasised the point that young adults on the autism spectrum were difficult to place in employment post high school for the following reasons: (1) Lack of early transition planning at the school level to access post school services, (2) confusion about disability diagnoses, support services available, and funding post school, and (3) limited employer knowledge of ASD. Collectively, a combination of organisational infrastructure at the school and socio-political level impacted effective service provision.

Discussion

The purpose of this chapter was to address the research question: *What are the successes and challenges during the transition to adulthood for young adults on the autism spectrum from the perspectives of service providers?* The present study explored service provider perceptions of successes and challenges during the transition to adulthood including independent living, post-secondary education, employment, social participation, and family intervention for young adults on the autism spectrum. Focus groups were chosen as a platform to observe interactive group discussions amongst service providers who shared similar and different experiences in supporting young adults on the autism spectrum. Thematic analysis was used to identify themes relevant to the transition phenomenon of interest.

Through the lens of Bronfenbrenner (1994), the present study identified three main themes within service providers' perceptions of successes and challenges during the transition process, *Collaborative Relationships, ASD Specific Challenges,* and *Organisational Influences*. Within the main theme of *Organisational Influences* there were two subthemes that reflected service provider interactions with young adults on the autism spectrum, *Interaction with the School System* and *Service Provider Infrastructure.* Within the macrosystem, these findings demonstrated that school infrastructure and transition planning determined the quality of service provision. With regards to *Service Provider Infrastructure,* disability policy, organisational funding, and meeting key performance indicators impacted effective service provision for young adults on the autism spectrum.

Additionally, the present study identified two subthemes related to *ASD Challenges*, first, *Service Provider Experience of ASD* and, second, *Employer Understanding of ASD*. These findings indicated that although service providers received limited formal training in understanding ASD, advocacy for their clients was a priority. However, on the contrary, employers focused on the challenges of employing young adults on the autism spectrum in limited work capacity and reduced productivity impacting the cost-benefits ratio for the employer.

The main theme of *Collaborative Relationships* emerged as a pivotal factor in facilitating service provision. Although young adults on the autism spectrum were at the centre of service delivery, communication and interaction with schools, families, and employers emerged as important facilitators of successful support across both focus groups, which concur with findings from Davies and Beamish (2009).

Summary

This chapter presented the analysis and findings from a focus group study with service providers, on their perspectives of successes and challenges in supporting young adults on the autism spectrum and families during the transition to adulthood in Study 4. The next chapter, Chapter 7, will present a general discussion collectively of key findings across the four studies in the present program of research, implications of study findings, as well as the unique contributions to knowledge, study strengths and limitations, key recommendations, future research directions, and conclusions.

Chapter 7 - General Discussion

The overall aim of this thesis was to explore barriers and facilitators to a successful transition to adulthood for young adults on the autism spectrum in Australia. During transition, navigating adult roles and responsibilities in post-secondary education, employment, functional independence, and social relationships are associated with increased independence, organisational, communication, and social skills which require adjusting to new settings. For young adults on the autism spectrum, difficulty coping with change is a hallmark of the condition. As such, the normative challenges and change associated with the transition to adulthood are compounded with multiple difficulties unique to ASD. Given the increase in ASD prevalence in Australia and heterogeneity of the condition, it is critical for key stakeholders to understand more about how individual young adults navigate the transition to adulthood, together with parent experiences, and service provider perspectives. This chapter will revisit the research questions within this program of research, present the key findings of the four studies conducted within this thesis, as well as the implications of study findings, unique contributions to knowledge, study strengths and limitations, key recommendations, future research directions, and conclusions.

Research Questions

Following the methodology of Creswell and Plano Clark (2011) a mixed-methods design was implemented to achieve the aims of the four studies in this thesis. Key findings emerged from each study, along with trends across studies. These findings will now be briefly summarised.

Research Question 1. What are the experiences of young adults on the autism spectrum during the transition to adulthood?

Study 1 identified four main themes associated with the transition process: *Embracing ASD Differences, Social Interaction, Employment,* and *Functional Independence.* Across the lifespan, the developmental period of adolescence is recognised as pivotal to building social networks, establishing friendships, and relationship formation (Arnett, 2014; Wehmeyer et al., 2010). Within the microsystem, such interpersonal interactions require social skills and participatory communication that pose challenges for young adults on the autism spectrum (Attwood, 2008; Barnhill, 2007). In their own words, all young adults expressed a desire for increased socialisation beyond their immediate and extended families that was often not being met. They spoke of a sense of loneliness and isolation at the lack of friendships, and equally so, expressed their determination in actively pursuing friendships and the frustration of achieving very little success. The social skills required in knowing what to say, and how to say it, in interactions with peers, and in the workplace emerged as an area of difficulty, and potential barrier, for all of the young adults interviewed. Indeed, difficulty in social interaction is a hallmark of ASD impacting daily interactions, and these findings corroborate with recent research by Higgins et al. (2008) and Pillay and Brownlow (2017).

Individuals on the autism spectrum have difficulty understanding their own feelings and feelings of others, and, as such, they may appear to be cold, literal, and concrete towards others (Attwood, 2008). Therefore, it might be difficult for neurotypical peers, support workers, professionals, and other individuals who interact with young adults on the autism spectrum to understand the need to have friends and to socialise. On the one hand, difficulty in social skills and social interaction associated with ASD make navigating friendships and social networks challenging, and individuals on the autism spectrum may appear unfriendly. On the other hand, consistent with a recent review, young adults in the present study expressed a need to explore friendships (Tobin et al., 2014). What was unexpected, was the extent of self-determination, which appeared to be a protective factor in managing their ASD differences, in actively seeking friendships by intentionally joining social groups at university, the formation of an online Facebook social group for adults on the autism spectrum, and joining an ASD support group. These actions by young adults in the present study mirrored findings by Müller et al. (2008) of joining ASD support groups and social groups to improve social interaction and increase social support. Indeed, young adults in their study, acknowledged an increase in social connectedness and social support by participating in groups that shared a common interest (Müller et al., 2008). Interestingly, seminal research by Howlin and Yates (1999) also highlighted the low-cost factor associated in forming social skills groups and informal support groups, which may be of significant benefit to young adults on the autism spectrum in improving social connectedness.

As ASD is characterised by restrictive behaviour and rigid routine, organising and managing living activities that change on a daily basis, such as finances and budgeting, time management, and meal preparation might be difficult for young adults on the autism spectrum (McCollum et al., 2016). As such, a sense of routine was important for all young adults as they spoke of role changes in shifting from the structured school setting to the university environment, in moving out of the family home, and in managing daily activities. First, with regards to managing daily activities, some young adults in the present study coped with some of their daily chores whilst others were dependent on families for support in organising and managing meals, finances, and doing the laundry. These findings concur with Adreon and Durocher (2007) who suggest that opportunities are provided at home and as part of school transition planning at high school, to include daily life skill preparation to promote self-sufficiency in adulthood for young adults on the autism spectrum. Notably, further support for the management of daily living skills, such as doing the laundry, can be found in a study by Barnhill (2016) who posits the development of specific transition based support programs for young adults on the autism spectrum at university campuses during summer holidays and orientation days.

Second, with regards to daily routine, navigating the change from a supportive, structured school setting to large university classes with seemingly no structure or defined class timetable, appeared overwhelming for some young adults. Indeed, it is known that disruption to routine is identified as a trigger to increased anxiety levels for individuals on the autism spectrum (Hendricks, 2010). As such, support with transitioning to university in both the academic and social realm, was highlighted by young adults as a need to improve satisfaction as a university student. More specifically, a lack of support staff knowledgeable in ASD emerged as a barrier in accessing social support at university. These findings align with recent research which indicated that specialised intervention strategies for young adults on the autism spectrum, within the social and communication realm, are needed by support staff at universities (Barnhill, 2016; Mitchell & Beresford, 2014; VanBergeijk et al., 2008). As such, professional training in ASD for staff in student support services would be beneficial to improve both academic and social support offered at university, which is in agreement with recent research by Barnhill (2016). Indeed, it might be perplexing for university support services without having the knowledge of ASD difficulties, to comprehend that students who are academically capable might need support with social interactions and communication (Hewitt, 2011; Zager & Alpern, 2010).

Internal struggles with acknowledging their differences, questioning their incapacities with peers, and battles with failure in the workplace emerged as key points of tension as participants spoke of low self-esteem, anxiety, depression, and inattention. The concept of *fitting in* was a recurrent motive between young adults as they questioned their differences and reflected on their challenges. This concept reverberated in participant reflections as they tried to reconcile childhood and adolescent feelings of being different and excluded from peer social circles. Indeed, according to Higgins et al. (2005), ASD is typically not identified by physical appearances. It might be that for this reason the young adults interviewed did "*look normal*" and did "*talk normal*" (Portway & Johnston, 2003, p. 435), but within their unique personalities was an underlying tension of social incapacities impacting low self-esteem, depression, and anxiety which concurs with findings by Barnhill (2007) and Ozsivadjian et al. (2014).

Research Question 2. What are the experiences of parents of young adults on the autism spectrum during the transition to adulthood?

Four key themes with associated subthemes emerged from the interview data with parents: *Family Challenges, Functional Independence, Support Experiences,* and *Family Advocacy*. A common narrative interwoven across all four themes was the strength and persistence of mothers in advocating for their young adult children across the school system, adult support services, in accessing financial support, and in seeking employment. Through their endeavours all mothers had a common goal, that of achieving some semblance of stability, security, and future success for their children in adulthood. Indeed, these findings corroborate with those by Pfeiffer et al.

(2017) in that parents in their study also highlighted future success and community integration as important factors for a positive QOL for their children on the autism spectrum.

Some factors of importance identified by mothers in achieving success as adults were completing high school with the recognition of individual capabilities, living independently with or without formal support with safety as a priority, having a real-life partner as opposed to a partner as caregiver, and overall being treated as equals with neurotypical peers in everyday life situations. Vehicles that would facilitate this transition revolved around: First, at the microsystem level, support at school, support at university, and support in the workplace; second, at the mesosystem level, school, employer, and the wider community to have an accurate understanding of ASD; third, at the macrosystem level, user-friendly access to support services; and fourth, at the exosystem level, increased knowledge of resources and financial support for both families and young adults on the autism spectrum.

Mothers were honest and acknowledged the challenges unique to their young adult children. Some of the challenges included difficulty driving, inability to access transport independently, limited knowledge of budgeting, and inappropriate social behaviour, as barriers to living and functioning independently in society, and indeed, the potential threat to their individual safety. However, mothers were also proactive in filling these gaps by teaching their children life skills from a young age. In particular, one mother highlighted how avoiding eye contact, associated with ASD, could be perceived as deceitful behaviour, and fuelled with alcohol on a night out, could have severe legal consequences for her young adult son. Indeed, parenting a child on the autism spectrum emerged as a stressful experience, as mothers faced developmental difficulties associated with adolescence and young adulthood such as alcohol abuse, as well as challenges specific to ASD, such as poor functional independence, and is echoed in previous research by Smith and Anderson (2014).

Some mothers raised concern with aggression amongst siblings, whilst others spoke of family support in managing aggressive behaviour and meltdowns. Within the theme of *Family Challenges*, the focus of the family was always on the young adult on the autism spectrum. Mothers wore most of the responsibility as primary caregivers, and some suffered socially and financially whilst others were mentally and physically fatigued with the constancy of having to fight systems throughout the young adult lifespan. Indeed, these findings further support research that mothers of children on the autism spectrum are at significant risk of increased stress, depression, physical, and emotional problems when compared to mothers of typically developing adolescents (Howlin & Moss, 2012; Seltzer, et al., 2010; Smith, Seltzer, & Greenberg, 2012). As such, it is imperative that parents of young adults transitioning to adulthood are provided with information relevant to post-school formal support and available resources to assist with family and individual challenges.

Some mothers wrestled with their constant need to support, facilitate, teach, and *hover* over all of their young adult children's life choices, to the point of blurring the line between being either a supportive parent or an overprotective mother. It appeared almost contradictory that young adults on the autism spectrum relied on intensive and continuous family support to facilitate their independence. Notably, this was apparent in Lua's to-and-fro rhetoric of her son Bob's dependence on her, which ultimately impacted her physical wellbeing. Nevertheless, mothers' persistence in advocating for their children emerged as a key factor in achieving some adult role markers of attending university, living independently, and managing relationships. Indeed, the importance of all mothers' advocacy is consistent with findings by

Moodie-Dyer et al. (2014) who reported that mothers in their study were determined in seeking support, and engaging in advocacy for their children on the autism spectrum.

Interwoven through all themes was a reverberating echo in all mothers' narrative of being let down over time by systemic procedures at all ecological levels of, initial ASD diagnosis, school, post-secondary education, employment, and disability support systems. Several studies have documented the hurdles faced by families of individuals on the autism spectrum, with many reporting the invisible nature of ASD impacting areas of support, limited access to disability funding, and greater unmet support needs (see for example Higgins et al., 2005; Hoogsteen & Woodgate, 2013; Moodie-Dyer et al., 2014).

Research Question 3. What factors are evident during the transition period that might be related to a successful or unsuccessful transition to adulthood?

Based on the exploratory sequential design (Creswell & Plano Clark, 2011), Study 3 extended on Study 1 and Study 2, where the qualitative findings from young adult and parent interviews were used to inform the development of the survey in Study 3. Collectively, the key qualitative findings that emerged from both parent and young adult interviews associated with transitions were, *Embracing ASD Differences, Social Interaction, Functional Independence, Support Experiences*, and *Employment*. Thus, the combination of both qualitative and quantitative methods to explore barriers and facilitators during the transition to adulthood provided a broad understanding of the research question. Further, a longitudinal case series design allowed for an examination of factors common to those young adults who showed improvements and those who showed deterioration in QOL over the 12-month transition period.

Study 3 examined the first hypothesis that further support will be found for the role of protective factors of receipt of transition planning at school, receipt of disability support services, social skills training, social support, and family advocacy in promoting a successful transition to employment, independent living, social inclusion, and good QOL. A case series analysis supported this hypothesis that ASD specific transition planning and interventions, skills development, parental involvement in transition planning, work experience placements, and support from service providers appeared to be protective factors for those young adults who experienced a successful transition, and enhances the key qualitative findings of *Support Experiences* and *Employment* from interviews with young adults and parents in Study 1 and Study 2.

The role of family advocacy was more complex. Whilst family advocacy emerged as a protective factor in all aspects of facilitating support at school, at university, and in access to disability support for those young adults who experienced successful transitions in Study 3, quite unexpectedly, it appeared to be a barrier in the group of young adults experiencing unsuccessful transition, specifically to post-secondary education. One possible explanation for this is the likelihood that support staff may be unaware of the communication and social interaction difficulties associated with ASD, and did not expect to interact with parents as they advocated for their young adult children during enrolment and for support. Interestingly, some mothers in Study 2 also experienced similar negative encounters from support staff at university. Specifically, a similar discrepancy was noted in recent research where parents were confronted with privacy laws in their attempts to communicate with university support staff regarding support for their young adult on the autism spectrum (Cai & Richdale, 2016). Such situations may be potentially avoided by having trained individuals who interact and support young adults on the autism spectrum. As Cai and Richdale (2016) note, the negative impacts through misunderstandings and limited support potentially have life changing implications, for example, in increased mental health issues, and in a worse-case scenario, young adults on the autism spectrum dropping out of university. Overall whilst family advocacy was identified as an important protective factor in Studies 1, 2, and 3, it might be the case that support services staff need to have an increased knowledge of ASD specific intervention, and that a collaborative approach with families is necessary to facilitate effective support in post-secondary education. Therefore, the combination of parental advocacy both as a barrier and facilitator during the transition process provides crucial evidence for educational and post-secondary institutions in developing support infrastructure and policy for individuals on the autism spectrum.

Furthermore, Study 3 examined the second hypothesis that further support will be found for the role of risk factors of lower functional independence, co-occurring depression and anxiety, limited social skills, and communication challenges. A case series analysis supported this hypothesis, and these risk factors were evident for both groups experiencing successful and unsuccessful transitions. Importantly, common across both groups experiencing successful or unsuccessful transition in Study 3, regardless of transition supports and interventions, co-occurring depression and anxiety emerged as risk factors to successful transition. Indeed, secondary difficulties of anxiety, depression, and low self-esteem emerged as risk factors in both Study 1 and Study 2. Thus, these findings provide confirmation of the impact of ASD challenges in social and communication difficulties, as well as co-occurring anxiety and depression as risk factors during the transition to adulthood.

Interestingly, common across both groups experiencing successful or unsuccessful transition in Study 3, was the importance of the diagnosis of an ASD and associated challenges that contributed to identity formation, self-awareness, and self-efficacy, potentially as a protective factor in navigating and managing transition challenges. As such, this finding further extends the theme of *Embracing ASD Differences* in Study 1 and Study 2. Of note, this level of self-awareness can also bring a different level of social problems associated with ASD disclosure in stigma and negativity, a strong sense of difference, and loss of friends.

Research Question 4: What are the successes and challenges during the transition to adulthood for young adults on the autism spectrum from the perspectives of service providers?

Within the macrosystem level of support, three key themes with associated subthemes emerged from focus group discussions amongst disability support providers. Within the main theme of *Collaborative Relationships*, *Family Challenges* emerged as a shared subtheme across service providers' perspectives that families experienced difficulty in accessing support due to a limited knowledge of services available. Indeed, this is a key concern that was highlighted by the Australian Advisory Board on ASD (2011). Through the lens of service providers, more often than not, ASD specific services were lacking and families were left to cope with service providers who had limited understanding of ASD and experienced challenges themselves in supporting both families and young adults on the autism spectrum. These findings align with Moodie-Dyer et al. (2014) who highlighted that a lack of information in accessing support resources and inappropriate support strategies by service providers untrained in ASD had a negative impact on parents. In the present study, the consequences of such a mismatch in service provision resulted in some families left deserted without formal support. Parents were then forced to take on the role of support provider, and in some cases experienced depression and anxiety. These findings are in agreement with Higgins et al. (2005) who found that caring for a child on the autism spectrum was demanding with many parents experiencing depression and anxiety. In addition, parents may not have the necessary skills to provide formal support for their young adult children (Mitchell & Beresford, 2014). Therefore, there is a need for targeted, individualised ASD support services that would alleviate a dependency on parents, and potentially protect their mental health and wellbeing.

Collectively, within a systems perspective, the pressure from the government on performance outcomes in meeting key performing indicators and financial implications was interwoven in all service provider experiences. Often, these government expectations were to the detriment of what was the in the best interest and effective intervention for the young adult. Within the key theme of *Organisational Influences*, service provider infrastructure across the macrosystem influenced how services were implemented. Some service providers demonstrated empathy towards the complex needs of young adults on the autism spectrum, whilst others articulated the harsh reality of choosing to work with *easier clients* so as to meet performance indicators to secure their future funding. Indeed, service providers emphasised the difficulty in attempting to match the needs and interests of the young adult on the autism spectrum with specific types of employment. Mostly, such exhaustive attempts involved developing a relationship with a potential employer, crafting a tailor-made job to suit specific interests, sensory needs, and level of social interaction, without a guarantee of success in the job.

Whilst employment is recognised as improving financial independence and alleviating a dependency on family support and the welfare system, service providers agreed that the perspectives of employers were crucial to employing and supporting young adults to be successful in their job. Notably, whilst service providers were empathetic to the needs of these individuals, on the contrary, employers focused on *deficits* and perceived ASD limitations as a barrier to workforce productivity impacting their cost-benefits ratio. These findings are in contrast to recent research that shows that employers value the honesty, trustworthiness, loyalty, and typically low levels of absenteeism of individuals on the autism spectrum (Hagner & Cooney, 2005; Hendricks, 2010; Stankova & Trajkovski, 2010). This suggests that employers may benefit from increased knowledge and awareness of the advantages of employing an individual on the autism spectrum. Further, an increase in employment of individuals on the autism spectrum would contribute to improved financial independence for the individual themselves, as well as a reduced dependency on the welfare system.

Interestingly, through service provider voices, a fundamental issue in support and intervention from the perspective of community health was exposed. More specifically, the co-occurring mental health and anxiety issues of young adults on the autism spectrum may not necessarily be supported by disability services once they reach adulthood. For instance, community health intervention teams have an explicit focus on support provision based on intellectual disabilities as measured by IQ, and as such, do not focus on developmental difficulties. Therefore, as ASD is a developmental condition, co-occurring support needs such as depression and anxiety of some young adults on the autism spectrum may not be specifically met. Therefore, for those young adults on the autism spectrum without co-occurring ID, there is a potential to slip between the cracks in service provision, especially at the crucial stage of entering young adulthood, where they may face an increased risk of co-occurring mental health challenges (Wehman, Schall, Carr, et al., 2014). Of note, these community health support requirements are linked to NDIS eligibility criteria in that individuals on the autism spectrum with low support needs according to the DSM-5 Level 1 (APA, 2013), are not eligible for disability support within the NDIS (Australian Department of Human Services, 2015). This is potentially problematic and would suggest that individuals on the autism spectrum with average to above average intellectual ability may find it difficult to have their needs recognised and access services within the NDIS.

Implications of Study Findings

In general, the young adults across Study 1 and Study 3 appeared to be limited not by their individual difficulties, but by the very systems charged with supporting them through their schooling, post high school activities, and transition to key adult roles within the community. Within an ecological framework, challenges associated with poor outcomes for young adults during transitions were due to first, insufficient professional attention to their *abilities* at the school and post school systemic level, second, limited knowledge of the developmental nature of ASD, and third, limited understanding of the implementation of individualised interventions that will facilitate successful outcomes in this population, particularly as they transition to adulthood. The implication of these findings suggests a comprehensive understanding of the nature of ASD as a lifelong developmental condition by all individuals who interact with the young adults on the autism spectrum, including family, teachers, peers, disability support staff, and workplace colleagues is crucial. In this way, the dual recognition of cognitive ability and autism specific challenges can be acknowledged, together with the associated difficulties in social interaction, communication, and fixations silently underpinning internal struggles with community integration, social inclusion, functional independence, and overall wellbeing.

Although some young adults in Study 3 showed success in transition and improvements in QOL over the 12-month transition period, all young adults in this study noted some level of difficulty with skills required to access paid employment, challenges in social and community integration, and organisational skills in functional daily living activities. Therefore, ongoing ASD specific intervention both at school and post-school may be beneficial. At the school level, intervention promoting social communication with peers, developing skills required in organisation, time management and budgeting, are specific skills that may help to foster success in the social, vocational, and post-secondary education domains during the transition period. The evidence from Study 3 suggests that knowledge of ASD specific skills intervention is important in informing ASD policy development and practice within disability support infrastructure and suggests that a transition focused education is important. These findings are of critical importance to a wide audience including educational institutions at a school and post-school level, policy developers, and families.

Parents of individuals on the autism spectrum play a pivotal role as caregivers, support providers, and advocates. However, the distress experienced by families through mothers' voices in Study 2 revealed their daily battles at a systemic level, and their plea was to government support systems to listen to their angst. Mothers' lived experiences provided compelling confirmation of the dependency of young adults on their families, impacting finances, family relationships, and overall mental health and wellbeing. Such personal experiences have implications at the macrosystem level, specifically in informing government disability infrastructure for support for families. More specifically, the benefits of targeted intervention with a focus on social support, community access, and employment to address ASD specific support needs will reduce dependency on families and caregivers, and potentially boost the economic system through increased productivity in the workforce. Overall, the development and implementation of such ASD specific services has implications for an improved cost-benefit to government and society at large. Collectively, implications of increased productivity in the workforce, improved financial independence, and increased self-esteem would alleviate dependency on an exhausted disability support system with improved QOL for young adults on the autism spectrum.

Across the mesosystem in Study 3, transition planning, support, and intervention with family involvement at the school level was crucial to a successful transition, which suggests the need for the role of parents to be clearly defined and included as part of support infrastructure within Australia. The finding that parental advocacy may become a potential barrier post-school is important, as it suggests that different support guidelines may be required for young adults on the autism spectrum during the transition period. The implication of this finding is that comprehensive transition support programs are implemented across post-secondary institutions specifically for individuals on the autism spectrum including ASD specific training for support services staff who interact with these individuals. Such specialist programs will fill gaps in support service particularly in the understanding of non-academic areas of organisation, social interaction, and communication difficulties.

Collectively, the study findings from this program of research emphasises the importance of a comprehensive mandated transition policy for all young adults on the autism spectrum. Such policy will enable early transitional support and planning at the school level, and fill the gaps in service provision during the transition period through continued access to support within the NDIS adult disability system. As such, knowledge of individual needs, some of which may be complex to include mental health needs, will be identified early in the transition process and supported by a multidimensional specialist transition team with ongoing support during the transition period. Finally, across Study 1 and Study 3 the finding that the diagnosis of an ASD and associated challenges contributed to identity formation, self-awareness, and self-efficacy has important implications for promoting self-determination and self-advocacy skills within the transition planning process.

Unique Contributions to Knowledge

This thesis has presented unique contributions to knowledge within an ecological framework, three of which are noteworthy. First, Bronfenbrenner’s Ecological Systems Theory (1994) conceptualises human development from an interactionist perspective between people and the environment as well as from a systems perspective in which different parts of the system affect each other. This program of research has captured the collective lived experiences across all systems within an ecological perspective, from young adults at the centre of the transition experience, families, and service providers. As such, the knowledge gathered from these individuals contributes a holistic in-depth understanding of successes and challenges within current disability support infrastructure. Such experiences provide first hand knowledge and insider perspectives of factors that facilitate or inhibit transitions across family, school, community, post-secondary education, and employment. In doing so, this research extends current knowledge of the successes and challenges during the transition to adulthood specifically within an Australian context.

Second, this thesis has recognised that regardless of cognitive ability, ASD is a heterogeneous developmental condition with wide scope of differences in individual, social, communication, and behavioural challenges with all young adults requiring support. As such, the present research provides a framework for the recognition of ASD as a distinct condition within the NDIS across all DSM-5 (APA, 2013) levels so that autism specific challenges in individuals with and without co-occurring ID are acknowledged and supported.

Third, collectively across this program of research, stigma, negativity, and exclusion were associated with individuals on the autism spectrum and families. An important contribution to existing ASD knowledge within a systemic level is the awareness of a *strengths* and *abilities* perspective in schools, post-secondary education, and employment to embrace a shift from a *deficit* and *impairment* lens towards the inclusion of young adults on the autism spectrum in all aspects of adult and community life. Finally, Study 3 provides compelling evidence of risk and protective factors during the transition to adulthood. Since risk and protective factors associated with young adults on the autism spectrum is relatively under-researched, that findings from the present research will contribute to the existing body of knowledge in this field.

Key Recommendations

Given the heterogeneity of ASD the transition experience is expected to be different for each young adult on the autism spectrum. Taken together, understanding the range of outcomes for the young adult population on the autism spectrum and their parents' perceptions will be of significance to key stakeholders in tailoring service delivery to meet the unique needs of these individuals. Therefore, in addressing the overall aim of this thesis in identifying barriers and facilitators to a successful transition to adulthood for young adults on the autism spectrum, understanding the social interactions, family relationships, and developmental skills required to function independently is valuable in contributing to the development of a multilayered understanding of interventions needed at the family, school, community, and systemic-policy level. Collectively, the barriers and facilitators identified in the present program of research in this thesis contributes this information through the following key recommendations across the ecological system:

At the microsystem level

1. Transition planning, skills intervention, and support in schools across all state and territories in Australia should demonstrate consistency underpinned by mandated Commonwealth law
2. Such policy should include areas of best practice in transition focused education to include students, parents, and interagency providers as key stakeholders during the transition to adulthood planning process

At the exosystem level

1. Families are provided with information on effective specialist support and access to resources from initial diagnosis through the transition to adulthood, across key areas of post-secondary education, employment, independent living, social inclusion, and community integration
2. The role of parents within a support capacity should be clearly articulated to ensure roles and responsibilities are acknowledged

At the mesosystem level

1. Dedicated ASD information programs should be implemented through government disability employment services to improve employer

awareness of ASD and benefits of supported employment for individuals on the autism spectrum

2. Community awareness of the skills-benefit of individuals on the autism spectrum both in the workplace and within the community to embrace a shift from a historically entrenched *deficit* to *abilities* perspective

At the macrosystem level

1. Capacity building and skills training to ensure an educated and informed service provider workforce, specific to the needs of individuals on the autism spectrum in the areas of co-occurring mental health issues, social support, communication difficulties, access to post-secondary education, employment, and independent living
2. Within the NDIS, recognition of ASD as a distinctive condition with unique supports and intervention across the developmental lifespan for all individuals on the autism spectrum across all levels of functioning as identified in the DSM-5 (APA, 2013)

Study Strengths and Limitations

Several strengths were evident in this program of research. First, the use of both qualitative and quantitative methods to explore barriers and facilitators to the transition to adulthood presents credibility in methodological triangulation in capturing and acknowledging multiple perspectives, as to how young adults experience the transition journey (Lincoln & Guba, 1986). Second, qualitative methodology provided a platform to listen to individual experiences, which are important in informing evidence-based practices across multiple systems. Third, a longitudinal case series design incorporating two assessment time points allowed for a detailed examination of the transition period to determine how QOL changed over this period. Further, the longitudinal design allowed for an examination of factors common to those who showed improvements and those who showed deterioration in QOL over the 12-month transition period. Such a detailed and in-depth examination is particularly valuable and informative given the vulnerability and difficulty associated with research in accessing the population with ASD. Fourth, a case series design allowed for a thorough examination of change in key areas for individual participants, as well as identification of risk and protective factors associated with the transition to adulthood. In addition, the use of the Reliable Change Index (Jacobson & Truax, 1991) to examine statistically reliable change applies a methodological rigour to the case series design in this research. Ultimately, the longitudinal case series design allowed for the findings of the qualitative studies to be examined over a 12-month transition period, within a small sample of target participants. Nevertheless, there are some limitations within the research that must be addressed.

First, given the heterogeneity of an ASD diagnosis, the young adults in the present study cannot necessarily be considered representative of the broader ASD population. As most of the young adults interviewed in Study 1 were engaged in tertiary study findings may be limited to this demographic of individuals. Second, due to the online and anonymous format of the survey in Study 3, a diagnosis of ASD without co-occurring ID could not be verified through access to intelligence scores. However, all participants in Study 1 and Study 3 completed high school in Australia and were recruited from ASD support organisations across Australia. This meant that a medical diagnosis of ASD had previously been verified either by the school disability support system or the ASD support organisation with which they were registered. Therefore, participants’ self-reported diagnosis was accepted as meeting the formal criterion for participation in the present research. Third, as Study 3 was a small-scale longitudinal survey, the type of statistical analysis that could be conducted was limited. Despite the common risk and protective factors identified across both groups in Study 3, it is difficult to understand the magnitude of effect due to the small sample size. Further, whilst in-depth interviews and a longitudinal case series design captured rich data from a wide variety of participants, it is difficult to generalise findings from the present program of research given the heterogeneity of an ASD diagnosis in specific behaviour traits, social skills, and cognitive ability ascribed to an individual. Thus, caution should be noted in comparing these findings with other young adults on the autism spectrum. Finally, as with all survey-based research, self-reported data may be subject to biases.

Future Directions

The outcomes of this program of research provide several avenues for future research. At the mesosystem level, a case series analysis indicated that transition planning, skills intervention, and family support at the school level underpinned successful pathways to post-secondary education and employment options after high school. However, Australian educational institutions have inconsistent approaches to transition planning, neither is there mandated Commonwealth law requiring the implementation of transition supports and interventions (Commonwealth of Australia, 2014; O’ Neill et al., 2016). Therefore, future studies would benefit by examining issues related to transition support for young adults on the autism spectrum, particularly within the mesosystem at the school level, and how these may be improved to incorporate transition best practice identified in the literature as mandated policy consistent across Australian states and territory.

Collaboration amongst such key stakeholders is essential, as the impact of a successful or unsuccessful transition to adulthood have far reaching consequences within the academic, psychological, occupational, and clinical realm. As such, future studies would benefit from integrated research across the school system, family network, and disability support service infrastructure, to address the complex transition issues as experienced by young adults on the autism spectrum and their families.

Within an ecological systems perspective, interpersonal relationships between family, friends, and the immediate environment contribute to the behaviour, functioning, and overall life satisfaction experienced by young adults on the autism spectrum (Bronfenbrenner, 1994; Schalock, 2004). Therefore, as families play a key role in advocating for and supporting young adults on the autism spectrum, the perspectives of fathers and siblings on their wants and needs during the transition process need to be heard in future studies. Whilst this was not an area of explicit focus of this thesis, it is an area that warrants further exploration given the crucial support role of families in the lives of the young adult children on the autism spectrum. Further, it may be valuable to consider how research with families of individuals with developmental disabilities may apply to families of young adults on the autism spectrum.

In addition, some of the young adults across Study 1 and Study 3 were diagnosed later in adolescence or in adulthood. As such, the present research provides a unique insight of adult outcomes in some young adults with average or above average intellectual ability who did not receive early intervention services but progressed through to high school completion. Therefore, future research would benefit from exploring the successes, challenges, and coping mechanisms of such individuals on the autism spectrum prior to a later diagnosis in adolescence or in adulthood.

Conclusions

At present, the Australian disability support system is transitioning to a new infrastructure in the NDIS. This change in disability support structure presents a pivotal opportunity for key stakeholders, government, and disability policy developers to identify and improve previous areas overlooked, specifically in the realm of identification and targeted intervention for young adults on the autism spectrum (Australian Advisory Board on ASD, 2011). Key goals of the NDIS are to improve levels of participation in society, greater access to competitive employment, a range of accommodation options to meet individual needs and circumstances, and a reduction in the financial gap between individuals with and without disabilities (Australian Department of Human Services, 2015). Ultimately, these goals seek to reduce social isolation and mental health concerns as experienced by individuals with disability so as to improve overall QOL. As such, the barriers and facilitators to workplace inclusion, independence, social, and economic participation as experienced by individuals on the autism spectrum would need to be accurately assessed and identified (Australian Advisory Board on ASD, 2012). It is therefore critical that the unique characteristics of ASD are considered within the development and implementation of the new infrastructure of the NDIS to ensure that individuals and families receive a support service that is sensitive to their needs. In addition, disability service providers would need to be cognisant of the individual needs of young adults on the autism spectrum. At present, the specific needs of young adults on the autism spectrum are blurred within a generalist NDIS model of eligibility and disability support. If indeed key goals of the NDIS are to improve social isolation and to increase access to employment so as to improve overall QOL for individuals with disabilities, it is important that the key recommendations from the current research in this thesis are considered.

In conclusion, this program of research identifies specific demographic, individual, and group characteristics that facilitate a successful transition to adulthood for young adults on the autism spectrum. At a systems level, this is important in informing family, disability organisations, and the NDIS strategic policy on tailored interventions to ensure a seamless transition to post-secondary education, employment, functional independence, social inclusion, and overall life satisfaction for young adults on the autism spectrum.

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Appendix A

University of Southern Queensland

Participant Information for USQ Research Project Interview
Young Adults on the autism spectrum aged (18-25)

Project Details

Title of Project: Young Adults on the Autism Spectrum in Australia: Transition to Adulthood

Human Research Ethics Approval Number: H15REA227

Research Team Contact Details

Principal Investigator Details	Supervisor Details
Ms Yosheen Pillay	Dr. Charlotte Brownlow
Email: Yosheen.Pillay@usq.edu.au	Email: Charlotte.Brownlow@usq.edu.u
Telephone:0412 554249	Telephone: (07) 4631 2982
Mobile: 0412554249	Mobile: 0448 828872

Description

This study is being undertaken as part of a PhD research Project.
The purpose of this study is to explore factors that enhance and factors that hinder a successful transition to adulthood for young adults with ASD in Australia aged 18-25 years. We would like to find out from you, what your experience of the transition process has been, post-high school. Specifically, we would like to know of your interactions and experiences with disability support services, support from your family and whether your diagnosis of ASD has had an impact on your transition after school.
The research team requests your assistance through a semi-structured interview in order to gain your individual perception of the transition experience directly. You must be aged 18-25, have a medical diagnosis of ASD without an intellectual disability, currently in the transition phase, and living in Australia.

Participation

- Your contribution will involve participation in a semi-structured interview that will take approximately 45-60 minutes of your time.

- The interview will take place at a time that is convenient to you.

- Please choose from one of the following options as to how you would like the interview to be conducted. Please indicate your choice by ticking a box.

☐Telephone interview
☐Online chat forum
☐Written response
☐Face-to-face

- Questions will include your experiences with disability support services after leaving school in exploring post school options and the family support you have had as you transition to adulthood.

- Additionally, we are interested as to whether your ASD has impacted in areas such as employment access, friendship and social networks and your living circumstances and arrangements.

- You may choose to use your own name, or you may choose to use a pseudonym to protect your privacy. If you would like the researcher to choose a pseudonym for you at the transcription stage then this will be done.

- The interview will be audio recorded.

- You will be provided an opportunity to review your interview transcript and add or remove any issues

- 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 destroyed.

- Withdrawal of data cannot occur once data analysis has commenced.

- 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 not immediately directly benefit you. However, the information you provide will contribute specialist planning and ASD support provision in the future.

Risks

There are minimal risks associated with your participation in this project. These include time imposition and low psychological risks.

<u>Time imposition:</u> We will require 45 minutes of your time to partake in one semi-structured interview. The interview will be conducted in a format and a time that is convenient for you

Psychological risk: There is a low risk of psychological issues. Some of the questions will require you to reflect on past experiences with disability services, your ASD and family support. It is possible that some experiences may trigger negative emotions.

Sometimes thinking about these 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 the USQ Clinic on 4631 1763 (Toowoomba) or 3470 4005 (Springfield). Lifeline support is available throughout Australia by calling 13 11 14. Headspace is a support organization available throughout Australia and offers online support, phone support or your local Headspace centre may be found by accessing the Headspace website at www.headspace.org.au.

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.
Audio recordings will be used for transcription purposes only, and will be destroyed after 5 years.
Professional transcription services will have access to the recording for transcription purposes, and confidentiality will be ensured.
The data collected in this project may be used in future research projects by the two researchers to further develop understandings of focused interests.

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.

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 Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au. The Ethics Coordinator 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 B

University of Southern Queensland

UNIVERSITY OF SOUTHERN QUEENSLAND AUSTRALIA

Consent Form for USQ Research Project Interview

Project Details

Title of Project: Young Adults with Autism Spectrum Disorder in Australia: Transition to Adulthood

Human Research Ethics Approval Number: H15REA227

Research Team Contact Details

Principal Investigator Details	**Other Investigator/Supervisor Details**
Ms Yosheen Pillay	Dr Charlotte Brownlow
EmailYosheen.Pillay@usq.edu.au	EmailCharlotte.Brownlow@usq.edu.au
Telephone: 0412554249	Telephone: (07) 4631 2982
Mobile: 0412554249	Mobile: 0448 828 872

Statement of Consent

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that the interview will be audio recorded.
- Understand that you are free to withdraw at any time, without comment or penalty.

- Understand that you can contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au if you do have any concern or complaint about the ethical conduct of this project.

- Are over 18 years of age

- Please indicate your age (tick one box) ☐18-20 ☐20-22 ☐22-25
- Have a medical diagnosis of high functioning ASD without any intellectual disability
- Agree to participate in the project.

Participant Name

Participant Signature

Date

Please return this sheet to a Research Team member prior to undertaking the interview.

Appendix C

University of Southern Queensland

Semi-structured Interview Questions-Young Adults on the autism spectrum

- Can you tell me a little bit about yourself? (What is it like to be on the autism spectrum)
- What are some of the challenges/difficulties that you faced after leaving school?
- How have you managed to overcome them?
- What are you currently doing?
- Do you receive any support or help with what you are doing?
- What are your experiences with disability support services (Centrelink etc) for example, in finding employment, accessing volunteer work or making friends/socialising?
- Did you have family support during high school? Can you explain.
- Did you have any family support after high school? Can you explain.
- Did your family assist you? e.g. in finding work
- Did your friends assist you? e.g. in accessing social activities?
- Does your ASD impact how you interact on a daily basis?
- Does your ASD impact on your ability to access employment, to pursue tertiary study, to friendships, to partners?
- Can you tell me about your social life? Do you have friends?
- What aspects of your ASD do you feel are difficult for you?
- Do you manage independently on a daily basis? Can you explain.

Appendix D

University Of Southern Queensland

Participant Information for USQ Research Project Interview
Parents of a young adult with ASD aged (18 to 25 years)

Project Details

Title of Project: Young Adults with Autism Spectrum Disorder in Australia: Transition to Adulthood

Human Research Ethics Approval Number: H15REA227

Research Team Contact Details

Principal Investigator Details	Supervisor Details
Ms Yosheen Pillay	Dr. Charlotte Brownlow
Email: Yosheen.Pillay@usq.edu.au	Email: Charlotte.Brownlow@usq.edu.u
Telephone:0412 554249	Telephone:(07) 4631 2982
Mobile: 0412554249	Mobile: 0448 828872

Description

This study is being undertaken as part of a PhD research Project.
The purpose of this study is to explore factors that enhance and factors that hinder a successful transition to adulthood for young adults with ASD in Australia aged 18-25 years. We would like to find out from you, what your experience of the transition process has been as a parent, during and post-high school.
Specifically, we would like to know of your interactions and experiences with disability support services, support from community, family and whether your child's diagnosis of ASD has had an impact on transition after school.
The research team requests your assistance through a semi-structured interview in order to gain your individual perception of the transition experience directly.

Participation

- Your contribution will involve participation in a semi-structured interview that will take approximately 45-60 minutes of your time.

- The interview will take place at a time that is convenient to you.

- Please choose from one of the following options as to how you would like the interview to be conducted. Please indicate your choice by ticking a box.

☐Telephone interview
☐Online chat forum
☐Written response
☐Face-to-face

- Questions will include you and your child’s experiences with disability support services after your child has left school in exploring post school options and the family support you have provided to your child as they transition to adulthood.

- Additionally, we are interested as to whether your child’s ASD has impacted in areas such as employment access, friendship and social networks and their living circumstances and arrangements.

- You may choose to use your own name, or you may choose to use a pseudonym to protect your privacy. If you would like the researcher to choose a pseudonym for you at the transcription stage then this will be done.

- The interview will be audio recorded.

- You will be provided an opportunity to review your interview transcript and add or remove any issues.

- 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 destroyed.

- Withdrawal of data cannot occur once data analysis has commenced.

- 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 not immediately directly benefit you or your child. However, the information you provide will contribute specialist planning and ASD support provision in the future.

Risks

There are minimal risks associated with your participation in this project. These include time imposition and low psychological risks.

Time imposition: We will require 45-60 minutes of your time to partake in one semi-structured interview. The interview will be conducted in a format and a time that is convenient for you

Psychological risk: There is a low risk of psychological issues. Some of the questions will require you to reflect on past experiences with disability services, your child's ASD and family support. It is possible that some experiences may trigger negative emotions.

Social risk: There is minimal social risk that will impact your relationship with your family. Some questions may require you to think of social relations you have experienced. It is possible that some of these relationships may trigger negative experiences.

Sometimes thinking about these 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 the USQ Clinic on 4631 1763 (Toowoomba) or 3470 4005 (Springfield). Lifeline support is available throughout Australia by calling 13 11 14. Headspace is a support organization available throughout Australia and offers online support, phone support or your local Headspace centre may be found by accessing the Headspace website at www.headspace.org.au.

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.
Audio recordings will be used for transcription purposes only, and will be destroyed after 5 years.
Professional transcription services will have access to the recording for transcription purposes, and confidentiality will be ensured.
The data collected in this project may be used in future research projects by the two researchers to further develop understandings of focused interests.

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.

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 Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au. The Ethics Coordinator 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 E

University of Southern Queensland

Parent Consent Form for USQ Research Project Interview

Project Details

Title of Project: Young Adults with Autism Spectrum Disorder in Australia: Transition to Adulthood

Human Research Ethics Approval Number: H15REA227

Research Team Contact Details

Principal Investigator Details	Other Investigator/Supervisor Details
Ms Yosheen Pillay	Dr Charlotte Brownlow
EmailYosheen.Pillay@usq.edu.au	EmailCharlotte.Brownlow@usq.edu.au
Telephone: 0412554249	Telephone: (07) 4631 2982
Mobile: 0412554249	Mobile: 0448 828 872

Statement of Consent

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that the interview will be audio recorded.
- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au if you do have any concern or complaint about the ethical conduct of this project.

- Have a child aged 18-25 years with a medical diagnosis of ASD without intellectual disability
- Please indicate the age of your child: ☐18-20 ☐20-22 ☐22-25
- Agree to participate in the project.

Participant Name	
Participant Signature	
Date	

Please return this sheet to a Research Team member prior to undertaking the interview.

Appendix F

UNIVERSITY OF SOUTHERN QUEENSLAND

Sample Semi-structured Interview Questions-Parents

1. Can you tell me a little bit about your family background?
2. Can you tell me a little bit about your child with ASD?
3. What are some of the challenges that you and your child faced whilst your child was at school?
4. Prompt: How have you managed to overcome them?
5. What are your experiences with disability support services for example, in helping your child finding employment, accessing volunteer work or making friends/socialising?
6. Did you support your child during the transition process? How did you do this?
7. Prompt: Did you assist your child e.g. in finding work
8. Prompt: Did your family assist your child? e.g. in accessing social activities?
9. Does your child's ASD impact how they interact on a daily basis? e.g. With friends, at work, at Uni?
10. Prompt: Does your child's ASD impact on their ability to access employment, to pursue tertiary study, to friendships, to partners?

Appendix G

ASD Longitudinal Survey

Start of Block: Participant Information Sheet

Q1.1 Young Adults with Autism Spectrum Disorder: Transition into Adulthood Transition is defined as the move from high school to tertiary study and/or employment, independent living and developing a social network that contributes to quality of life as a young adult. The research team requests your assistance through the completion of the online survey in order to gain your individual perception of the transition experience directly. We will require approximately 30 minutes of your time to complete the survey. The purpose of this project is to identify facilitators and barriers to a successful transition for young adults aged 18-25 with high functioning Autism Spectrum Disorder (that is without intellectual disability), as well as to assess if these factors change over time. We would also like to invite you to complete the same survey one year later so that we can see if there have been any changes in your transition process. If you would like to partake in the survey one year later please provide your consent for the survey and please provide us with your e-mail address in the space at the end of this page.

Participation 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 choose to share this survey with other young adults with ASD. The survey will remain open until the end of June 2016. Data analysis will commence in September 2016. If you do wish to withdraw from this project, please contact the Principal Researcher (contact details at the bottom of this form). The data collected in this project may be used in future research projects by the researchers to further develop understandings of transition processes 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, or the organisation where you accessed the survey. It is expected that this project will not immediately directly benefit you. However, the information you provide will contribute specialist planning and ASD support provision in the future.

Privacy and Confidentiality

All comments and responses will be treated confidentially unless required by law.

Any data collected as a part of this project will be stored securely as per University of Southern Queensland's Research Data Management Management policy http://www.usq.edu.au/privacy/privacy-statement. If you require further information, please contact ethics@usq.edu.au There is also some risk of psychological issues. Some of the questions will require you to reflect on past experiences with disability services, your ASD and family support. It is possible that some experiences may trigger negative emotions. Sometimes thinking about these sorts of issues raised in the survey can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately please contact the USQ Clinic on 4631 1763 (Toowoomba) or 3470 4005 (Springfield). Lifeline support is available throughout Australia by calling 13 11 14. Headspace is a support organisation available throughout Australia and offers online support, phone support or your local Headspace centre may be found by accessing the Headspace website at www.headspace.org.au

You may choose to use your name or a pseudonym, but no information will be provided in the write up as to whether the names used are actual names. Researcher Contact Details

Principal Investigator Details Yosheen Pillay Email: Yosheen.Pillay@usq.edu.au Mobile: 0412554249	**Supervisor Details** Dr Charlotte Brownlow EmailCharlotte.Brownlow@us.edu.au Telephone: 07 46312982

Q1.2 Please provide your Name or a Pseudonym in the space below.

____

Q1.3 If you would like to participate in the survey one year later, please provide us with your email address in the space below

____

About You

Q1.4 **About You**
Please answer the following questions about yourself. Some require you to place a tick in the box. Others ask you to write an answer in the space provided.

Q1.5 **Part A: Demographic Information**

✱

Q1.6 Please indicate your age in years.

____

Q1.7 What is your gender

○ Male (1)

○ Female (2)

Q1.8 **Current living circumstances**: Please indicate if you are:

○ Living with a partner (1)

○ Living independently (2)

○ Living with friends/roommates (3)

○ Living with parents (4)

✱

Q1.9 Please write the name of the town you live in

____

Q1.10 **Relationship status**: Please indicate if you are in a:

○ Relationship (1)

○ Married (2)

○ Single (3)

Q1.11 Do you receive a disability pension/allowance from the Australian Government?

○ Yes (1)

○ No (2)

Q1.12 **Part B: Employment Status**

Q1.13 Are you currently in paid employment?

○ Yes (1)

○ No (2)

Skip To: Q1.14 If Are you currently in paid employment? = Yes

Skip To: Q1.18 If Are you currently in paid employment? = No

Q1.14 What is your job description?

____

Q1.15 How long have you been employed at this job?

____

Q1.16 What is your weekly take-home pay

- ○ Less than $50 (1)
- ○ $50-$100 (2)
- ○ $100-$150 (3)
- ○ over $200 (4)

Q1.17 What is the average number of hours that you work per week?

- ○ Less than 10 hours (1)
- ○ Between 10-20 hours (2)
- ○ Between 20-30 hours (3)
- ○ More than 30 hours (4)

Q1.18 **Part C: Daily Activities**

Q1.19 What is your daily activity

○ Stay home with parents (1)

○ Stay home with friends (2)

○ Stay home with caregiver (3)

Q1.20 Please give a brief description of activities you engage in whilst you are at home

____

Q1.21 Do you currently attend a community day centre supported by a disability organisation

○ Yes (1)

○ No (2)

Skip To: Q1.23 If Do you currently attend a community day centre supported by a disability organisation = No

Q1.22 How many hours a week do you attend the day centre?

○ Less than 10 hours (1)

○ Between 10-20 hours (2)

○ Between 20-30 hours (3)

○ More than 30 hours (4)

Q1.23 Are you enrolled in tertiary study?

○ Yes (1)

○ No (2)

Skip To: Q1.25 If Are you enrolled in tertiary study? = No

Q1.24 What is your program of study? Please choose one.

- ○ University Degree (1)
- ○ TAFE Diploma (2)
- ○ TAFE Certificate (3)
- ○ Other (4)

Q1.25 **Part D: Individual Characteristics**

Q1.26 What is your diagnosis?

- ○ Autism Spectrum Disorder (1)
- ○ Intellectual Disability (2)
- ○ Both ASD and Intellectual Disability (3)

Q1.27 At what age were you diagnosed with ASD?

____

Q1.28 What type of school did you attend?

- ○ State High School (1)
- ○ State High School Special Education Unit (2)
- ○ State Special School (3)
- ○ Private School (4)

Q1.29 Please indicate the highest educational qualifications you have

○ University Qualification (1)

○ TAFE Qualification (2)

○ Graduate Diploma (3)

○ Finished Year 12 (4)

Q1.30 Did you receive any of the following interventions at school. Tick as many that apply

☐ Behaviour support (1)

☐ Social Skills training (2)

☐ Life skills training (3)

☐ Independent Living Skills Training (4)

☐ None (5)

Q1.31 Did you receive any of the following interventions outside of school?

☐ Behaviour Support (1)

☐ Social Skills Training (2)

☐ Life Skills Training (3)

☐ Independent Living Skills Training (4)

Q1.32 Did you have a Transition Plan at school?

○ Yes (1)

○ No (2)

Skip To: Q1.34 If Did you have a Transition Plan at school? = No

---

Q1.33 Was your family involved in your transition planning meetings at school?

○ Yes (1)

○ No (2)

Q1.34 Did you engage in work experience whilst at school?

○ Yes (1)

○ No (2)

Q1.35 How many work experiences did you have whilst at school?

____

Q1.36 Did you receive any support form an external agency, for example, an employment agency, in seeking employment whilst at school?

○ Yes (1)

○ No (2)

End of Block: Participant Information Sheet/About You

Start of Block: Block 2 Quality of Life: Satisfaction

Q2.1
Overall would you say that life:

○ Brings out the best in you (1)

○ Treats you like everybody else (2)

○ Doesn't give you a chance (3)

Q2.2 How much fun and enjoyment do you get out of life?

○ A lot (1)

○ A moderate amount (2)

○ A little (3)

Q2.3 Compared to others, are you:

○ Better off (1)

○ about the same (2)

○ Less well off (3)

Q2.4 Are most of the things that happen to you:

○ Rewarding (1)

○ Acceptable (2)

○ Disappointing (3)

Q2.5 How satisfied are you with your current home or living arrangement

○ Very satisfied (1)

○ Somewhat satisfied (2)

○ Unsatisfied (3)

Q2.6 Do you have more or fewer problems than other people?

- ○ Fewer (1)
- ○ The same (2)
- ○ More (3)

Q2.7 How many times a month do you feel lonely

- ○ Seldom (not more than once or twice) (1)
- ○ Occasionally (5 to 6 times a month) (2)
- ○ Frequently (once or twice a week) (3)

Q2.8 Do you ever feel out of place in social situations?

- ○ Seldom (1)
- ○ Sometimes (2)
- ○ Usually (3)

Q2.9 How successful do you think you are compared to others?

- ○ more successful (1)
- ○ about as successful (2)
- ○ less successful (3)

Q2.10 Do your family members make you feel

- ○ An important part of the family (1)
- ○ Sometimes a part of the family (2)
- ○ Like an outsider (3)

Q2.11 Can you describe how you feel about your life at this point in time

____

End of Block: Block 2 Quality of Life: Satisfaction

Start of Block: Block 3 Competence/Productivity

Q3.1 How well did your educational or training program prepare you for what you are doing now?

○ Very well (1)

○ Somewhat (2)

○ Not well at all (3)

Q3.2 Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?

○ Yes (1)

○ Probably (2)

○ No (3)

○ Currently unemployed (4)

Skip To: End of Block If Do you feel your job or other daily activity is worthwhile and relevant to either yourself or oth... = Currently unemployed

Q3.3 How good do you feel you are at your job

○ Very good (1)

○ Somewhat good (2)

○ Im having trouble on my job (3)

Q3.4 How do people treat you at your job

○ The same as all employees (1)

○ Somewhat differently (2)

○ Very differently (3)

Q3.5 How satisfied are you with the skills and experiences you have gained from your job

○ Extremely satisfied (1)

○ Slightly satisfied (2)

○ Extremely dissatisfied (3)

Q3.6 Are you learning skills that will get you a different or better job?

○ Yes (1)

○ Maybe (2)

○ No (3)

Q3.7 Do you feel you receive fair pay for your work

○ Definitely yes (1)

○ Sometimes (2)

○ Definitely not (3)

Q3.8 Does your job provide you with enough money to buy the things you want

○ Yes (1)

○ Not really (2)

○ No (3)

Q3.9 How satisfied are you with the benefits you receive at the workplace

○ Extremely satisfied (1)

○ Moderately satisfied (2)

○ Extremely dissatisfied (3)

Q3.10 How closely supervised are you on your job

○ Seldom (1)

○ Frequently (2)

○ Constantly (3)

Q3.11 Can you describe how your daily activities/employment make you feel?

____

End of Block: Block 3 Competence/Productivity

Start of Block: Block 4 Empowerment/Independence

Q4.1 How did you decide to do the job or other activities that you do now

○ Because of pay, benefits or interests (1)

○ Only thing available (2)

○ Someone else chose it for me (3)

Q4.2 Who decides how you spend your money

○ I do (1)

○ I do with assistance from others (2)

○ Never on my own (3)

Q4.3 How do you use health care facilities

○ On my own (1)

○ Accompanied by someone (2)

○ Never on my own (3)

Q4.4 How much control do you have over things you do every day, like going to bed, eating, and what you do for fun?

○ Complete (1)

○ Some (2)

○ Little (3)

Q4.5 When can friends visit you at home

○ Often (1)

○ Only when someone else is home (2)

○ Only on certain days (3)

Q4.6 Do you have a key to your home

○ Yes (1)

○ Sometimes I am given one (2)

○ No (3)

Q4.7 Can you have a pet if you want

- ○ Yes (1)
- ○ I will need to ask permission (2)
- ○ No (3)

Q4.8 Do you have a guardian

- ○ Yes (1)
- ○ Only for some decisions (2)
- ○ No (3)

Q4.9 Are there people living with you who sometimes hurt you, pester you, scare you, or make you angry

- ○ Yes (1)
- ○ Yes, and those problems occur once a month or once a week (2)
- ○ No (3)

Q4.10 Overall would you say that your life is

- ○ Free (1)
- ○ Planned for you (2)
- ○ Cannot usually do what you want (3)

Q4.11 Can you describe the extent to which you are able to function independently on a daily basis? eg. getting yourself to work, making your own meals

____

End of Block: Block 4 Empowerment/Independence

Start of Block: Block 5 Social Belonging/Community Integration

Q5.1 How many community organisations do you belong to

○ 2-3 (1)

○ 1 (2)

○ None (3)

Skip To: Q5.3 If How many community organisations do you belong to = None

Q5.2 How satisfied are you with the organisations that you belong to

○ Extremely satisfied (1)

○ Somewhat satisfied (2)

○ Dissatisfied (3)

Q5.3 Do you worry about what people expect of you

○ Sometimes (1)

○ Seldom (2)

○ Never (3)

Q5.4 How many times per week do you talk to (or associate with) your neighbors, either in the yard or in their home?

○ Sometimes (1)

○ Seldom (2)

○ Never (3)

Q5.5 Do you have friends over to visit

○ Often (1)

○ Sometimes (2)

○ Never (3)

Q5.6 How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?

○ 3-4 per month (1)

○ 1-2 per month (2)

○ Less than 1 per month (3)

Q5.7 Do you participate actively in those recreational activities

○ Most of the time (1)

○ Half of the time (2)

○ Rarely (3)

Q5.8 What about opportunities for dating or marriage?

○ I am married, or have the opportunity to date anyone I choose (1)

○ I have limited opportunities to date or marry (2)

○ I have no opportunity to date or marry (3)

Q5.9 How do your neighbours treat you?

○ Very good (invite you to activities, coffee, etc.) (1)

○ Fair (say hello) (2)

○ Bad (avoid you) (3)

Q5.10 Overall you would say that your life is

○ Very worthwhile (1)

○ Okay (2)

○ Useless (3)

Q5.11 How would you describe your involvement socially with friends, family and the community?

____

End of Block: Block 5 Social Belonging/Community Integration

Start of Block: Block 5 Perceived Social Support

Q6.1 Significant Other

	Very strongly disagree (1)	Strongly disagree (2)	Mildly disagree (3)	Neutral (4)	Mildly agree (5)	Strongly agree (6)	Very strongly agree (7)
There is a special person around when I am in need (1)	○	○	○	○	○	○	○
There is a special person with whom I can share joys and sorrows (2)	○	○	○	○	○	○	○
I have a special person who is a real source of comfort to me. (3)	○	○	○	○	○	○	○
There is a special person in my life who cares about my feelings (4)	○	○	○	○	○	○	○

Q6.2 If you have a partner/spouse, how would you describe your relationship?

____

Q6.3 Family

	Very strongly disagree (1)	Strongly disagree (2)	Mildly disagree (3)	Neutral (4)	Mildly agree (5)	Strongly agree (6)	Very strongly agree (7)
My family really tries to help me (1)	○	○	○	○	○	○	○
I get the emotional help & support I need from my family (2)	○	○	○	○	○	○	○
I can talk about my problems with my family. (3)	○	○	○	○	○	○	○
My family is willing to help me make decisions (4)	○	○	○	○	○	○	○

Q6.4 How would you describe your relationship with your parents and your siblings?

____

Q6.5 Friends

	Very strongly disagree (1)	Strongly disagree (2)	Mildly disagree (3)	Neutral (4)	Mildly agree (5)	Strongly agree (6)	Very strongly agree (7)
My friends really try to help me (1)	○	○	○	○	○	○	○
I can count on my friends when things go wrong. (2)	○	○	○	○	○	○	○
I have friends with whom I can share my joys and sorrows. (3)	○	○	○	○	○	○	○
I can talk about my problems with my friends (4)	○	○	○	○	○	○	○

Q6.6 How would you describe your relationship with your friends?

____

End of Block: Block 5 Perceived Social Support

Start of Block: Consent Form

Q87 I acknowledge that I:

- ☐ Am aged between 18-25 (1)
- ☐ Have ASD without intellectual disability (2)
- ☐ Am Australian (3)
- ☐ Am currently transitioning from school to post-school options
- ☐ By clicking on the submit button I give consent to participate in the survey at both time points (4)

End of Block: Consent Form

Appendix H

University of Southern Queensland

Participant Information for USQ Research Project
Survey Questionnaire

Project Details

Title of Project: Young Adults with Autism Spectrum Disorder in Australia:
Transition to Adulthood
Human Research Ethics Approval Number: H16REA039

Research Team Contact Details

Principal Investigator Details	**Supervisor Details**
Yosheen Pillay	Dr Charlotte Brownlow
Email: Yosheen.Pillay@usq.edu.au	EmailCharlotte.Brownlow@us.edu.au
Mobile: 0412554249	Telephone: 46312982

Description

This project is being undertaken as part of PhD thesis.
The purpose of this project is to identify facilitators and barriers to a successful transition for young adults out of high school, as well as to assess if these factors change over time (e.g. if there are continued barriers, emergence of new barriers/facilitators), and how the combination of barriers and facilitators over time contribute to successful transition one year later. To participate in the survey, you must be aged 18-25, have a medical diagnosis of ASD without an intellectual disability, currently in the transition phase, and living in Australia.
The research team requests your assistance through the completion of the online questionnaire in order to gain your individual perception of the transition experience directly.

Participation

Your participation will involve completion of an online questionnaire that will take approximately 30 minutes of your time.

Questions will include transition planning that you received at school, your current daily occupation, employment, how you feel about your quality of life and the support that you receive from family, friends and others in your life.

We would also like to invite you to complete the same questionnaire one year later so that we can see if there have been any changes in your transition process. If you would like to partake in the survey one year later, please provide us with your consent and e-mail address.

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. Please note, that if you wish to withdraw from the project after you have submitted your responses, the Research Team are unable to remove your data from the project. If you do wish to withdraw from this project, please contact the Principal Researcher (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 not immediately directly benefit you. However, the information you provide will contribute specialist planning and ASD support provision in the future.

Risks

Time imposition: We will require approximately 30 minutes of your time to complete the questionnaire.

Psychological risk: There is a low risk of psychological issues. Some of the questions will require you to reflect on past experiences with disability services, your ASD and family support. It is possible that some experiences may trigger negative emotions.

Sometimes thinking about these sorts of issues raised in the survey can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately please contact the USQ Clinic on 4631 1763 (Toowoomba) or 3470 4005 (Springfield). Lifeline support is available throughout Australia by calling 13 11 14. Headspace is a support organization available throughout Australia and offers online support, phone support or your local Headspace centre may be found by accessing the Headspace website at www.headspace.org.au

Privacy and Confidentiality

All comments and responses will be treated confidentially unless required by law.

The names of individual persons are not required in any of the responses.

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

Clicking on the ‘Submit’ button at the conclusion of the questionnaire is accepted as an indication of your consent to participate in this project at both time points.

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 Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au. The Ethics Coordinator 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 I

University of Southern Queensland

Participant Information for USQ Research Project
Focus Group
Disability Support Services

Project Details

Title of Project: Young Adults with Autism Spectrum Disorder in Australia: Transition to Adulthood
Human Research Ethics Approval Number: H16REA141

Research Team Contact Details

Principal Investigator Details
Yosheen Pillay
Email: Yosheen.Pillay@usq.edu.au
Mobile: 0412554249

Supervisor Details
Dr Charlotte Brownlow
EmailCharlotte.Brownlow@us.edu.au
Telephone: (07) 46312982

Description

This project is being undertaken as part of a PhD Thesis.

Transition is conceptualised as the shift from school to employment, post-school education, independent living and social interaction as a young adult.

Disability support services have a crucial role in facilitating a transition to adulthood for young adults with ASD aged (18-25).

The purpose of this study is to explore disability support services experiences in supporting and interacting with young adults with ASD and their families during the transition process.

The research team requests your assistance through the participation in a focus group discussion with other interested disability support service providers.

Participation

Your participation will involve contributing your perceptions and experiences regarding your interactions with young adults with ASD and their families during the transition process after high school.

The focus group will be conducted as an online group discussion that will take approximately one hour of your time.

The focus group will take place on
(TIME AND DATE)

Venue: USQ Ipswich Library, Meeting Room
11 Salisbury Road

Questions will include:

1. What are the factors that facilitate successful transition to adulthood for young adults with ASD, from the perspectives of disability support services?

2. What are the factors that inhibit successful transition to adulthood for young adults with ASD, from the perspectives of disability support services?

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 wish to withdraw from the project, 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, or the disability service provider that you are part of.

Expected Benefits

It is expected that this project will not immediately directly benefit you. However, the information you provide will contribute specialist planning for disability support services, employment agencies and ASD support provision in the future.

Risks

There are minimal risks associated with your participation in this project. These include:

Social Risk: Some questions may require you to think of social relations that you have experienced in supporting young adults with ASD and their families during the transition process. It is possible that some of these relationships may trigger negative experiences. However, it is expected that social risk will be minimal It is possible that you may know other participants professionally.

Time imposition: You will be required to commit 1 hour of your time to the focus group discussion.

Sometimes thinking about the sorts of issues raised in the focus group can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately please contact Lifeline on 13 11 14. 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.

All participants will remain anonymous throughout the study, and no information will be included in the final reporting that will identify either individuals or organisations.

The data collected in this project may be used in future research projects by the two researchers to further develop understandings of focused interests.

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 the principal researcher prior to participating in your focus group.

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 Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au. The Ethics Coordinator 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 J

University of Southern Queensland

Consent Form for USQ Research Project
Focus Group

Project Details

Title of Project: Young Adults with Autism Spectrum Disorder in Australia: Transition to Adulthood

Human Research Ethics Approval Number: H16REA141

Research Team Contact Details

Principal Investigator Details

Yosheen Pillay
Email: Yosheen.Pillay@usq.edu.au
Mobile: 0412554249

Supervisor Details

Dr Charlotte Brownlow
EmailCharlotte.Brownlow@us.edu.au
Telephone: (07) 46312982

Statement of Consent

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that the focus group will be audio recorded.
- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that the data collected in this project may be used in future research projects by the two researchers to further develop understandings of focused interests.

- Understand that you can contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au if you do have any concern or complaint about the ethical conduct of this project.

- Are over 18 years of age

- Agree to participate in the project.

Chosen Pseudonym	
Participant Signature	
Date	

Please return this sheet to a Research Team member prior to undertaking the focus group.

Appendix K

UNIVERSITY OF SOUTHERN QUEENSLAND

Focus Group Questions

Disability Support Services

1. What are the factors that facilitate successful transition to adulthood for young adults with ASD, from the perspectives of disability support services?

2. What are the factors that inhibit successful transition to adulthood for young adults with ASD, from the perspectives of disability support services?

3. Can you describe any special support provisions that you have made for young adults with ASD to access funding? Eg. My Future, My life or the NDIS?

4. Can you describe your role in linking families with specialist ASD support services? Eg. Social skills groups, literacy and numeracy groups or respite services?

5. Can you describe your experiences in providing social or emotional support to families of young adults with ASD? Eg accessing specialist community services

6. Can you explain your role in the transition from high school to after school options with young adults with ASD that you have supported?

Employment Service Providers

1.What are the factors that facilitate successful transition to adulthood for young adults with ASD, from the perspectives of employment service providers?

2. What are the factors that inhibit successful transition to adulthood for young adults with ASD, from the perspectives of employment service providers?

3.What were some of your experiences in supporting young adults with ASD to access paid employment?

4.Can you describe your experiences with employers in seeking employment for young adults with ASD?

5. Can you describe any support that you may have provided for young adults with ASD in the workplace? Eg behaviour support, travel training to get to work?

6. What were some of your experiences in working with families of young adults with ASD in seeking employment?