# ‘I THINK YOU NEED TO BE A HELICOPTER PARENT’.

# HOW MOTHERS OF NEURODIVERSE CHILDREN UNDERSTAND THEIR CHILD’S SCHOOLING EXPERIENCES, AND THEIR OWN ROLE IN THEIR CHILD’S EDUCATION

A Thesis submitted by

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# ABSTRACT

There is widespread concern over the mental health of young people; consequently, there is a current focus on social-emotional wellbeing in Australian education policies. Research indicates that academic pressure and feeling socially isolated at school are sources of anxiety for the majority of Australian adolescents. This is particularly true for students with Neurodevelopmental Disorders – or neurodiverse students – whose learning, social-emotional or behavioural difficulties make them highly vulnerable in school environments.

Involving parents in their children's schooling, and encouraging parents to be engaged in their children's learning, are also prioritised in national and state education policies. However, decades of research has established that effective and collaborative parent-school partnerships are difficult to achieve, especially for parents of students with complex and additional needs.

This qualitative phenomenological study aimed to gain a better understanding of the lived experiences of neurodiverse students and their parents. Interpretative Phenomenological Analysis (IPA) was employed in order to answer the following research question and five sub-questions: *How do the participants understand their neurodiverse child's experiences in high school settings, and their role in supporting their child's education?* (1) How did the participants describe and explain their child's experiences at school? (2) How did the participants describe their own experiences of participating in their child's education? (3) How might the participants experiences be interpreted? (4) What principles might be drawn from these interpretations to contribute to current understandings of effective parent-school relationships? (5) How do the findings contribute to current support practices for neurodiverse students and more effective parent-school partnerships?

Five mothers of neurodiverse adolescents, who attended mainstream schools in regional and rural Queensland, participated in semi-structured interviews. A detailed examination of the data, using IPA, revealed that:

1) Academic failure and social isolation were common experiences for these adolescents and had negative impacts on their wellbeing.

2) The participants attributed their child’s significant anxiety to a poor ‘fit’ between the mainstream school environment and their learning and social-emotional needs.

3) The participants perceived that their role in the parent-school relationship was to safeguard their child’s current and future wellbeing through concerted engagement in their child’s cognitive and social development, and active involvement at school.

4) The participants struggled to find authoritative information about their child’s difficulties or access remedial medical, mental health and allied health services.

5) The participants felt excluded from decisions around their child’s education and that their parent knowledge was ignored by educators.

The study findings suggest that schools should focus on the social-emotional wellbeing of neurodiverse adolescents to the same extent as their academic achievements; and should do so in supportive and developmentally appropriate environments. The study also emphasised the importance of working partnerships between educators and parents that are based on the sharing of knowledge about neurodiverse children, and mutual respect for expertise and experience.

The study findings contributed to a set of principles and practices to inform educators, school leaders and education authorities about the importance of creating high school environments that are developmentally appropriate to the needs of neurodiverse students and that best support their wellbeing. These principles also relate to building stronger partnerships with parents. Limitations and implications for future research are considered.

# CERTIFICATION OF THESIS

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

Principal Supervisor: Dr Lindy Anne Abawi

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

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# TABLE OF CONTENTS

# LIST OF FIGURES

# LIST OF TABLES

# GLOSSARY

Adolescence

‘Adolescence is the period of physical, cognitive, and social maturation between childhood and adulthood. Although there is variation in how societies and cultures define adolescence, its beginning is marked by the onset of puberty and its end is generally considered as the uptake of stable adult roles. The World Health Organization (WHO) defines an adolescent as any person between ages 10 and 19’ (The Centre for Adolescent Health, Murdoch Children’s Research Institute (MCRI), 2018a, p.6).

Adjustment

The *Disability Standards for Education 2005* state that this is ‘a measure or action taken to assist a student with disability to participate in education and training on the same basis as other students’ (Department of Education and Training, 2018). These include modifications to the curriculum, instruction or environment.

Advocate

‘Parent advocacy is concerned with advocating on issues that affect the person with a disability and their family. The focus is on the needs of the person with a disability, not the parents or family’ (Queensland Advocacy Incorporated, 2020, qai.org.au).

Allied Health Professionals

In the current study, this referred to speech pathologists, occupational therapists and physiotherapists.

Anxiety disorders

Anxiety disorders differ from normal feelings of nervousness or anxiousness, and involve fear or anxiety that is out of proportion to the situation or age inappropriate and hinders an individual’s ability to function normally. Anxiety disorders include generalized anxiety disorder, panic disorder, specific phobias, agoraphobia, social anxiety disorder and separation anxiety disorder. Anxiety disorders can lead to internalising problems such as avoidance (American Psychiatric Association, 2020).

Behaviour problems

Behaviour problems refer to displays of behaviour that deviate from social norms and are socially disapproved of by those in authority. Behaviour problems can be the symptomatic expression of emotional problems or interpersonal maladjustment. Behaviour problems are sometimes described as externalising problems (MCRI, 2018a, p.6).

Bullying

Bullying is repeated verbal, physical, social or psychological aggressive behaviour by a person or group directed towards a less powerful person or group that is intended to cause harm, distress or fear. Bullying is sometimes referred to as peer victimisation (MCRI, 2018a, p.6).

Co-morbid

Two or more medical conditions that exist simultaneously with and usually independently of one another (Merriam Webster).

Diagnosis

The Department of Education, Queensland states that, to be eligible for the Education Adjustment Program (EAP), a student must receive a verification in one of six EAP disability categories (see Disability). Depending on the EAP category, the impairment must be diagnosed or identified by an authorised specialist either within or outside of the department (Department of Education, 2019a).

Disability

The discourse around disability is a contested issue. In Queensland schools and education policy, ‘students with disabilities’ refers to students who require additional support for complex needs arising from one or more diagnosable and long-term impairments. The current study uses the term ‘students with disability/ies’ when citing policy or research. In other cases, it refers, for example, to ‘students with ASD’ where specified in either the study data or research literature. Where this was not specified, or general principles were being drawn from the research, the phrases ‘students with special educational needs (SEN)’, young people with SEN or ‘SEN students’ are used. This works in the educational setting, but outside that, there is no uniformity in the language of medical and mental health, education policy and practice, or even in the way people with ‘disabilities’, ‘different abilities’ or ‘special or additional needs’, and their families, refer to themselves or their children.

Education Adjustment Program (EAP)

In Queensland government schools, there are six categories of disability: Autism Spectrum Disorder (ASD); hearing impairment; intellectual impairment; physical impairment; speech–language impairment; vision impairment. These students require significant adjustments to their learning environment, teaching or learning activities and the EAP is the process of identifying and responding to those needs.

Emotional problems

‘Emotional problems refer to symptoms of anxiety and depression such as sadness, loneliness, worrying, feelings of worthlessness and anxiousness. Emotional problems are sometimes described as internalising problems’ (MCRI, 2018a, p.7).

Guidance Officer

‘A specialist teacher who provides advice and counselling on educational, behavioural, vocational, personal, social, family, and mental health and wellbeing issues.’ Guidance Officers may conduct a range of psychoeducational assessments, depending on their qualifications. (Queensland Government, 2019).

Individual Education Plan (IEP)

An IEP is required for children with disability to document adjustments and strategies that enable them to participate in learning on the same basis as their peers. (*Disability Standards for Education 2005*, p. 9, available at: http://education.gov.au/disability-standards-education).

IEP Process

A collaborative and consultative process, between teachers, parents/carers and health professionals, of documenting the child’s needs and developing the IEP.

Internalising disorders

*See Anxiety disorders*

Learning

‘Student learning encompasses the knowledge, skills, and abilities that students attain as a result of their involvement in education. Academic progress is a key component of this, but this concept also includes important life skills not directly measured by standardised tests such as resilience, self-efficacy, perseverance and social skills’ (MCRIa, 2018, p.7).

Learning disability or disorder

*See Specific Learning Disorder or Disability*

Learning differences

*See Specific Learning Disorder or Disability*

Learning journey

The participants’ metaphor used in the current study to describe their children’s school-based and home-based education. The latter included speech pathology interventions, academic tuition, music lessons, sports coaching and team participation – whatever the parents believed would assist with the child’s cognitive and social development and support their schooling journey.

Learning progress

Improvements in knowledge, skills, and abilities that students attain over time as a result of their involvement in education (MCRI, 2018a, p.7).

Learning Support Teacher

Teachers who work with classroom teachers to support students with additional learning needs in mainstream classes. They also work with these students in groups or one-to-one situations.

Medical health professionals

The identification of Neurodevelopmental Disorders involves General Practitioners, paediatricians and psychiatrists.

Mental health problems

'Mental health problems, sometimes referred to as mental illness or mental disorders, are a wide range of conditions that affect mood, thinking and behaviour. Many people will have symptoms of poor mental health from time to time, but it becomes a problem (or disorder) when the symptoms are on-going and affect the ability to function' (MCRI, 2018b, p.7).

Mental health professionals

In the current study this referred to General Practitioners, paediatricians and psychiatrists (who are involved in the identification and management of Neurodevelopmental Disorders).

NAPLAN

'The National Assessment Program – Literacy and Numeracy (NAPLAN) is an annual national assessment for all students in Years 3, 5, 7, and 9. All students in these year levels are expected to participate in tests in reading, writing, language conventions (spelling, grammar and punctuation) and numeracy. All government and non-government education authorities have contributed to the development of NAPLAN materials' (Australian Curriculum and Reporting Authority, 2016).

Neurodevelopmental Disorders

Neurodevelopmental Disorders are 'a group of conditions with onset in the developmental period. The disorders typically manifest early in development, … and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning. The range of developmental deficits varies from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence'. (DSM-5 Handbook of Differential Diagnosis, American Psychiatric Association, 2013).

Neurodiversity

Neurodiversity conceptualises what is medically diagnosed as a Neurodevelopmental Disorder, as a neurological difference. This difference is recognised in terms of all other forms of human diversity.

OP (Overall positions)

The OP score was used until 2019 as a tertiary entrance score for Queensland students who had completed Grade 12. A student's OP score indicated their position in rank order based on their overall achievement in Authority subjects.

Parents

In the literature discussion this refers to parents and carers. In the study, it referred to the child's birth mother and father.

Programme for International Student Assessment (PISA)

PISA is 'an international assessment measuring student performance in reading, mathematical and scientific literacy'. It has been conducted every three years since 2000 and compares student results from participating Organisation for Economic Co-operation and Development (OECD) countries. Its purpose is to improve student outcomes (Australian Council of Education Research, 2018).

School engagement/disengagement

'School engagement refers to a student's' relationship with school, school staff, other students and learning. It includes behavioural, emotional and cognitive components; a highly engaged student will participate in academic and social activities, will have a sense of belonging or connection with school, and will be motivated in their learning. Engagement is measured on a continuum with the lower part of the distribution considered to be disengaged. Disengagement is characterised by low attendance and participation, a lack of motivation for learning and low connection with teachers and school' (MCRI, 2018b, p.7).

School learning environment

In the current study this referred to instruction, learning tasks, assessment, teaching and learning resources that occur within the classroom.

School physical environment

In the current study this referred to the physical space; type and placement of desks, chairs and fittings such as carpets; elements that create background noise, such as fans, air conditioners, electronic whiteboards, projectors; and decorations such as posters, students' work and mobiles. These are important considerations for students with sensory processing or attention issues.

This also referred to the shared spaces outside the classroom such as walkways, playgrounds and lunch sheds.

School social environment

In the current study this referred to organised social groupings such as study pals, assessment partners or work groups; seating arrangements; and informal friendship or other social groups that occur within the classroom. This also referred to organised social groupings such as sports teams or school-based social clubs; and informal friendship or other social groups that occur outside the classroom.

Schooling journey

The participants' metaphor, used throughout the current study, to describe their children's progress through school.

Social and emotional skills

The 'abilities to regulate one's thoughts, emotions and behaviour…. and concern how people manage their emotions, perceive themselves and engage with others' (OECD, 2019, p.4).

Special Education Teacher

Specialist teachers who have additional training in the needs of students with disabilities and learning difficulties. Some schools have separate Special Education Units where these teachers work with students who have high levels of need.

Specific Learning Disorder

The DSM-5 classifies a Specific Learning Disorder as one or more difficulties in learning and using academic skills, lasting six months or more. Although the individual is of 'average' (or above average) intelligence, their skills in these areas are measurably below peer achievement levels, despite targeted interventions. Areas of difficulty include reading; reading comprehension; spelling; writing; understanding numbers or calculation; mathematical reasoning.

In Australia, conditions such as Dyslexia are usually referred to as Specific Learning Difficulties. This is the term used throughout this thesis unless referencing the DSM-5. In America, conditions such as Dyslexia are usually referred to as Specific Learning Disabilities. In the United Kingdom, a Learning Disability is an Intellectual Disability, that is, an IQ below 70.

Social-emotional wellbeing

The 'experience of positive behaviours and emotions, as well as how the individual adapts and copes with daily challenges (through resilience and coping skills) while leading a fulfilling life' (AIHW, 2018, Indicator 18).

SPELD Queensland

A not-for profit organisation supporting people with neurologically based difficulties in learning. SPELD refers to conditions such as Dyslexia as 'learning differences'. SPELD is variously 'SPELD' and 'Speld' even within their own website. It is capitalised in this thesis.

Teacher aide

Also known as teaching assistants or educational assistants. These staff members assist classroom teachers with preparing educational materials or equipment; may support small groups or individual students in the classroom or may be assigned to individual students to allow them to participate in the mainstream classroom.

Wellbeing

A multidisciplinary concept that includes objective domains such as physical health, material wealth and housing, and the more subjective domains of emotional, psychological, social and spiritual wellbeing.

Wellbecoming

A term that describes a student's future wellbeing.

# CHAPTER 1: INTRODUCTION

## 1.1. Introduction

When I began this study, there was a resounding silence from the parents I had hoped would participate in my research. Nobody, it seemed, wanted to discuss what it is like to parent a child with learning, social or behavioural difficulties and with anxiety related to those difficulties; or what it is like to interact with that child's school. And this surprised me, because I had only recently attended a conference for parents of children with Special Educational Needs (SEN) at which everyone on my table (and I should say, they were mostly mothers) wanted to share the story of their difficulties with education and medical professionals. Eventually, I realised I was using the wrong approach to attract my study participants – I was going through the schools with which they had an ambiguous and often uneasy relationship. It took time, and changes to the proposed study, but eventually I found my participants, or rather, they found me. And they would state, 'I have a story and I want you to tell other people what it is like for me, for my family, for my child'. I started with one parent's account and ended up hearing so many heartbreaking stories: about the emotional work of parenting (Miller, 2017); about adversarial relationships with education authorities and professionals; about committing a life to appointments and interventions; about the loneliness associated with parenting a child who does not always fit in; and about knowing an absolute sense of responsibility, regardless of perceived social and professional snubs, to advocate for that child.

This chapter provides a background and rationale for the current study and sketches a broad overview of the Australian context against which these parents' stories will be told. This includes constructions of disability and neurodiversity; an outline of current concerns for the social-emotional health of neurodiverse adolescents; and the role parents and schools play in their support. The phenomenon of intensive contemporary parenting is then introduced. These concepts underpin the current study, contextualise parent-school relationships in the 21st century, and help explain parents' motives for involvement in their child's school. The chapter discusses the research focus and purpose, establishes the researcher connection to the research and outlines the evolution of the research questions. It concludes with an outline of the thesis structure.

This chapter is preceded by an explanation of terminology used throughout the thesis.

## 1.2. Background and statement of the problem

### 1.2.1. Conceptualising disability and neurodiversity

> *Held back: the experiences of students with disabilities in Victorian schools* (2012) … found that … disability discrimination was still occurring in schools and students with disabilities face significant barriers to achieving equal outcomes.
> (Victorian Equal Opportunity and Human Rights Commission [The Commission], 2017)

> Unsuccessful school performance is a key risk factor in children developing mental health problems.
> (Kay-Lambkin, Kemp, Stafford & Hazell, 2007)

The *Disability Standards for Education 2005* articulate the Australian Government's commitment to ensuring that 'students with disability are able to access and participate in education on the same basis as other students' (Department of Education, Employment and Workplace Relations [DEEWR], 2012, p. iii). In 2017, the Nationally Consistent Collection of Data on School Students with Disability [NCCD], identified that 724,624 (18.8%) students in Australian schools received an educational adjustment due to disability (Education Council, 2017, p. 1). Of those students, 44% received 'Supplementary Adjustments' or modifications to teaching practices, learning materials and/or buildings and classrooms; and 33% received support within 'Quality Differentiated Teaching Practice', or negotiated and minor adjustments to teaching practice, learning materials and environment (Education Council, 2017, Table 6). In other words, most Australian students who are identified as 'disabled' are included in a mainstream classroom with varying degrees of learning support and adjustments to teaching practices, learning activities and assessment tasks.

A significant issue with the NCCD data collection is that it is based on 'the broad definition of disability' used in the *Disability Discrimination Act 1992* (DDA) (Education Council, 2017, p. 1) and the *Disability Standards for Education 2005* (DEEWR, 2012), and is heavily reliant on schools' understanding of that definition and the intent of the legislation and policy (Education Council, 2017, p. 1). The Australian Bureau of Statistics (2018a) defines disability as a limitation, restriction or impairment which has lasted, or is likely to last, for at least six months and restricts everyday activities. However, the differing positions, among teachers and schools, around definitions of disability and who is disabled reflects a general absence of consensus in Australia around interpretations of what constitutes a 'limitation, restriction or impairment' (Department of Education and Training, 2015a; [DET], 2012; Urbis, 2015). And this is a problem. The way in which disability is defined and discussed determines government provision of school funding and support, influences parents' and teachers' expectations of student performance and participation (Haegele & Hodge, 2016; Zaretsky, 2005), and legitimises specific forms of parental involvement in school.

This lack of consensus stems from differences in the way 'disability' is conceptualised in broader societal contexts – discussions around disability are situated in either a biomedical or social perspective. The medical, or individual, model of disability (Oliver, 1990, 2013) operates from the perspective of physical or cognitive deficit that is situated within the individual, has biopsychological origins and is identified through medical or psychometric assessment and diagnosis. This normative view contrasts the 'disabled' individual with 'normal' individuals – the further the 'disabled' individual deviates from the norm, the greater the level of impairment, or severity of disability. Medical, psychological or education interventions aim to 'fix' the impairment via treatment or interventions (Cochran-Smith & Dudley-Marling, 2012; Haegele & Hodge, 2016).

The social model of disability (Oliver, 1990, 2013) disputes the normative view of normal and deficit and focuses instead on the social barriers and prejudices that prevent 'differently abled' people from fully participating in education, the workforce and society in general ("Disability: Beyond the medical model", 2009; Oliver & Barnes, 2012).

The classification, as 'disabled', of students with 'ambiguous, controversial, and invisible social, emotional, and behavioral disorders' (Blum, 2007, p. 204) is particularly problematic. This is partly because diagnosis and diagnostic labels form a double-edged sword that can provide resources and support but, at the same time, segregate students from their peers and condemn them to a role of 'otherness' (Broomhead, 2013; Gillman, Hayman & Swain, 2010; Lauchlan & Boyle, 2007). It is also because concepts of what constitutes a 'harmful difference' are not stable but are relevant to time and place (Akhtar & Jaswal, 2013, p. 1); that is, the difference between deficit and advantage is subjective (Armstrong, 2014; Austin & Pisano, 2017). In most western nations, Neurodevelopmental Disorders, including Autism Spectrum Disorder (ASD), Attention Deficit Hyperactive Disorder (ADHD) and Specific Learning Difficulties (SLDs), are considered to confer a distinct disadvantage.

The 2015 Census data (ABS, 2015a) estimated that one in 150 Australians have ASD. However, that figure could be as high as one in 70, considering changes to diagnostic criteria and recent research findings (Autism Spectrum Australia [Aspect], 2018). ADHD Australia (2019) estimates that around 5% of Australian children have a diagnosis of ADHD and the Australian Dyslexia Association estimates that approximately 10% of the population is affected by Dyslexia, or SLDs with impairment in reading. However North American research suggests that possibly one in five are on the continuum of mild to severe Dyslexia (ADA, 2019). The differences in these prevalence rates results from current uncertainties around the characteristics of, and inconsistent diagnostic approaches for ASD (Randall et al., 2016), ADHD (Franke et al., 2018) and SLDs (Moll, Kunze, Neuhoff, Bruder & Shulte-Korne, 2014).

In the current study, the participants' children were all diagnosed, in primary school, with Neurodevelopmental Disorders which included ADHD, SLDs, high functioning ASD and Non-Verbal Learning Disorder (NVLD). The children's common circumstance was anxiety: in all cases, their anxiety had been identified by their treating medical or mental health specialist as an aspect of their condition, and related to the learning, social-emotional or behavioural difficulties that characterise Neurodevelopmental Disorders. High levels of anxiety are closely linked to ASD (Rosbrook & Whittingham, 2010; Wigham, Barton, Parr & Rodgers, 2017), ADHD (Maric, Bexkens & Bogels, 2018; Schatz & Rostain, 2006) and SLDs (Leitão et al., 2017) and more than one child in the study had multiple diagnoses. Research consistently indicates that it is more common than not that individuals experience more than one condition, with co-morbid anxiety (Antshel & Russo, 2019; Eicher & Gruen, 2015; Mammarella et al., 2016; Masceretti et al., 2017; Reale et al., 2017).

For example, a child might have a diagnosis of ADHD and Dyslexia and experience anxiety. This type of overlap or 'syndrome-mix' (Kutscher, 2014) makes it difficult to separate the causal Neurodevelopmental Disorder from its impact on the child's schooling experience as there is a complicated relationship between a student's cognitive, behavioural and social abilities and the anxiety they experience in the school setting. These students may have externalising problems – behavioural outbursts that derive from poor impulse control (ADHD) or sensory overload (ASD); internalising problems such as social or generalised anxiety arising from the school social or learning context (ASD, SLD, NVLD); or degrees and combinations of both (Storch et al., 2015).

While each of these disorders present significant challenges for the individual within the learning, physical and social environments of the classroom, the playground and beyond the school boundaries, there are no physical signs or symptoms to differentiate these students from their peers (Osterholm, Nash & Kritsonis, 2007). Because their difference is not immediately apparent to teachers, other students and members of the wider school community, the difficulties of students with 'invisible disabilities' are not always recognised (Alexander-Passe, 2018; Davis, 2005; Sherlock-Shangraw, 2013; Valeras, 2010).

The legitimacy, (mis)diagnosis and over-diagnosis of Neurodevelopmental Disorders are contested and controversial issues (Australian Institute of Family Studies [AIFS], 2018; Hiscock et al., 2017; Partridge, Lucke, & Hall, 2014). However, the current study operates on the premise that there is a neurological basis for these adolescents' different ways of thinking, learning and behaviour (Brooks, 2014; Shaywitz, Ferrer & Shaywitz, 2018; Waldie & Saunders, 2014). Another, social, assumption underpinned the research: that this difference is construed as a disability is relevant to particular contexts, such as the school classroom or playground. Thus, discussions around disability and difference can be understood from the perspective of biology and social contexts. A bio-ecological perspective of disability acknowledges the dynamic interaction between an adolescent's biological characteristics and the contexts in which they live, play and learn (Bronfenbrenner, 1977, 1986, 1992, 2001a; World Health Organization [WHO], 2011).

Classifying neurocognitive differences as Neurodevelopmental Disorders or disabilities in the research literature, and in legislation and policy, conveys the actual and felt disadvantage for the individual. However, both expressions make it difficult to think of these adolescents in terms of their strengths, or even neutrally, rather than in terms of their deficits. Very many children and adults with neurocognitive difference function in the 'normal' range of intelligence (that is, very high to very low) and some of the world's greatest thinkers and most creative minds have Neurodevelopmental 'Disorders'. However, their most significant disabilities are 'shame, fear and believing you are a loser' (Hallowell in Strauss, 2016, n.p.).

The current study is based on the idea that all students represent the human continuum of socio-economic, ethnic and racial difference or diversity. This includes neurocognitive diversity and, accordingly, when discussing the participants' children, I refer to them as being 'neurodiverse' (Jaarsma & Welin, 2012; Singer, 2017) rather than having a Neurodevelopmental Disorder. Neurodiversity is a term with clinical and biosocial claims (Masataka, 2017; Organisation for Economic Cooperation and Development [OECD], 2017a) and the increasing use of 'diversity' and 'difference' in policy statements signals a general attitudinal shift. However, this does not mean that schools necessarily value diversity or emphasise the positives and potentials of difference (Deloitte. Access Economics [Deloitte], 2017; Forlin, Chambers, Loreman, Deppeler & Sharma, 2013).

As there are inconsistencies in defining 'disability', there are also inconsistencies in defining 'inclusion' and in conceptualising the way students with complex and additional needs should be included in mainstream schools (Anderson & Boyle, 2015; Department of Education, 2018b; Zaretsky, 2005). On the one hand, inclusion is a principle of social justice, equity and effective educational practice (United Nations Educational Scientific and Cultural Organisation [UNESCO], 2015): education policy upholds anti-discrimination legislation and, nominally, supports equal access to educational opportunities. On the other, inclusion can be token and underpinned by rationalist principles: students with complex and diverse needs may have the right to access mainstream schooling but reality does not always match rhetoric (Iacono, Keeffe, Kenny & McKinstry, 2019). Most Australian education authorities appear to operate somewhere in the middle – their policies are informed by principles of social justice, but policies differ across states and implementation is constrained by existing school structures and the capacity of teachers to support and include children with disabilities in mainstream classrooms (Forlin et al., 2013).

The current study was interested in how parents of neurodiverse students work within – and around – these constraints, while supporting their child's academic and social-emotional wellbeing. Parents of SEN students who are eligible for an Individual Education Plan (IEP) are highly involved in the development and review of their child's learning program at school (Department of Education, 2018a, 2019a). However, neurodiverse students do not always fit within Educational Adjustment Program (EAP) guidelines for disability support – currently, students with a medical diagnosis of ASD are eligible for an IEP in Queensland but students with ADHD and SLDs are considered to have 'learning difficulties' (Department of Education, 2018e) and rely on their teacher's ability to make appropriate adjustments, the school's resources and the degree and type of additional support available (Australian Curriculum and Reporting Authority [ACARA], 2012, 2019).

This is clearly an important issue for classroom teachers and schools, but also for these students who, with the right support, could become achievers and contributors to the community. However, according to the National Assessment Program – Literacy and Numeracy (NAPLAN) results, SEN students systematically underachieve at school, with an average difference of one to two years of learning (Deloitte, 2017), are less likely to complete Year 12 (ABS, 2009), and typically experience adverse life experiences and limited opportunities compared to their typically developing peers (Macdonald, Deacon & Merchant, 2016; Underwood, 2018). Specifically, neurodiverse students are overly represented in suspension and exclusion from school (The Commission, 2012) and teachers consistently report, in educational settings around the world, that they find it difficult to support these students' complex needs (de Boer, Pijb and Minnaerta, 2011). As parents experience their child's stigma and distress vicariously (Manago, Davis & Goar, 2017), the parents of neurodiverse students clearly have good reason to be concerned about their child's schooling experiences and long-term outcomes.

It is important to understand how their concerns might affect these parents' interactions with school professionals and members of the wider school community.

Given the complexities involved in diagnosing Neurodevelopmental Disorders, and the inclusion of neurodiverse students in schools, these are very individual parental experiences that need to be explored on an individual basis.

### 1.2.2. Concerns for mental health and wellbeing

> ‘Experience during adolescence predicts very strongly how young people will be doing at age thirty. If you had a certain number of mental health problems during the transition from youth to adulthood, you will have fewer friends, you are more likely to not have completed your education, you will be earning less money – if indeed you have got a job, you might be on disability support, you might be homeless. And you might be dead – from suicide.’
>
> (McGorry, 2017)

The social-emotional wellbeing of young people is a growing concern, with data from large-scale studies indicating that mental health problems and low wellbeing are increasingly prevalent amongst young people in Australia and worldwide (Australian Institute of Health and Welfare [AIHW], 2018; Australian Research Alliance for Children and Youth [ARACY], 2018; WHO, 2013). A recent report on the mental health of Australia’s youth population indicates that the incidence of young people at risk of ‘a probable serious mental illness’ has increased by a ‘statistically significant’ amount over the past five years (Bullot, Cave, Fildes, Hall & Plummer, 2017). And the Australian counselling and support service Kidshelpline has reported a ‘steady’ increase since 2012 in the proportion of children or young people assessed as experiencing a mental health disorder (Yourtown, 2018, p. xiv).

Current Australian research suggests that between 13% and 25% of Australian adolescents experience a mental health disorder (Bowman, McKinstry & McGorry, 2017; Lawrence et al., 2016; Bullot et al., 2017). While experts debate whether this is an increase in actual mental health problems or an increase in adolescent reporting (Carr-Gregg in Ferguson, 2019), the overall picture is troubling and gives credibility to media reports of an ‘anxiety epidemic’ among young Australians (King, 2019; Lang, 2017).

As Seligman (2011) suggests, these findings are paradoxical: national indicators on the wellbeing of young people that relate to physical health, learning and development, families and communities, and safety and security are generally positive (AIHW, 2018). In 2020 most Australian adolescents benefit from the nation’s domestic wealth (AIHW, 2019; Saunders, Bradbury & Wong, 2016) and an increasing life expectancy – Australians are more likely to die from ‘lifestyle’ diseases than the epidemics or industrial injuries that afflicted their ancestors (AIHW, 2018). While the Australian population has increased steadily and the cultural and ethnic composition of Australian society has undergone dramatic changes, Australian adolescents nevertheless live in a relatively tolerant, peaceful and socially cohesive society (Markus, 2018). Australia ranks in the top or middle third of OECD countries in measures of economic prosperity and health (ARACY, 2018).

And yet, in this ‘lucky country’ anxiety disorders and depressive disorders are the second and third highest cause of burden of disease among young Australians aged 5 to 24 years. These disorders often result in more serious mental health problems: the leading cause of total burden in the 15 to 24-year age group is suicide and self-inflicted injuries (AIHW, 2018).

The apparent incongruity of such psychological distress, in such a fortunate nation, leads newspaper editorials and media commentators to regularly dismiss today’s teenagers – ‘Post-Millennials’, ‘iGeneration’ or ‘Generation Z’ – as lacking resilience (Donnelly, 2014; Donoughue, 2017). Cutler, Reavely and Jorm (2017) analysed the Australian Broadcasting Corporation’s 2015 quiz ‘How mental-health smart are you?’ and found that, thanks to public education campaigns, respondents were quite knowledgeable about depression. However, they had less understanding about anxiety; in particular, they were uncertain about the point at which anxiety went beyond ‘normal’ boundaries and became life-affecting. Despite public education and significant increases in government investment in mental health services for young people (Hunt, 2019), there is evidently some remaining contention, and misperception, around the issue of adolescent anxiety.

Adolescence is a time of psycho-sexual, social and physical transition and it is not uncommon for young people to experience emotional swings (Department of Social Services [DSS], 2019); indeed, the turbulence of the adolescent’s emotional state has been a consistent theme in literary and scientific writing. Anxiety is a normal emotion that all people experience when they perceive threat or danger (Hudson & McKinnon, 2017). It is also normal to experience some emotional, physical and behavioural response to this perceived or real threat. Negative and anxious feelings become problematic and a ‘disorder’ when they dominate an adolescent’s life and prevent them from participating in activities that their peers enjoy (Hudson & McKinnon, 2017). Anxiety, and other mental health disorders limit life potential and, apart from the immediate distress felt by the individual, impose long term costs (Furber et al., 2015; Bullot et al., 2017). Students experiencing mental health disorders face significant challenges at school and around 40% will not complete secondary education (Bowman, et al., 2017). For these individuals there are major and life-long social, emotional and physical health and wellbeing impacts and collective impacts on the nation’s health and welfare systems (Council of Australian Governments [COAG], 2009).

Adolescence is a critical period for the onset of mental health issues (Robinson, Bailey, Browne, Cox & Hooper, 2016; Guy, Furber, Leach & Segal, 2016; Furber et al., 2015; McGorry, Purcell, Hickie & Jorm, 2007) and most ‘modifiable’ mental illnesses begin before adulthood (Guy et al., 2016, p.1147). The WHO (2018) estimates that ‘half of all mental illnesses begin by the age of 14 and three-quarters by the mid-20s’. Childhood and adolescence are obviously crucial periods for early intervention and prevention of adult mental illness (McGorry et al., 2007; Segal, Guy & Furber, 2017; WHO, 2013). However, Australian mental health researchers are still concerned that ‘very little [is known] about the mental health and welfare of young people’ (Rosenberg, in Ferguson, 2019, p.10).

In Australia, the dominant paradigm for explaining differing mental states is the medical model: divergent and negative moods, thoughts and feelings are viewed in terms of pathology and disease (O’Donovan, Casey, van der Veen & Boschen, 2013). A reductionist perspective separates mind from body, individual from environment and history, and fails to accommodate biopsychosocial influences (Middleton & Moncrief, 2019). Adolescent anxiety disorders and other mental health disorders can also be understood from a bio-ecological perspective: as the result of interactions between an individual’s characteristics, the immediate interpersonal environments of family, friends and school and the broader socio-political, economic and cultural environment (ARACY, 2018; Bronfenbrenner, 1977, 1986, 2001a; Guy et al., 2016; Kemp, Langer & Tompson, 2016).

An individual’s temperament, genetic predisposition, physical health and intellectual ability are risk factors in child and adolescent mental health disorders (Kemp et al., 2016); so are environmental factors that contribute to childhood adversity such as a family’s socio-economic status, parental employment status and family dysfunction (ABS, 2015b; Bullot et al., 2017). Being an indigenous Australian or living in a rural or remote region of Australia increases the adolescent’s risk of developing a mental health disorder (Ivancic et al., 2018; Twizeyemariya, Guy, Furber & Segal, 2017) and parent characteristics, parenting behaviours (Waite, Whittington & Creswell, 2014) and family conflict (Carlisle et al., 2018) are also implicated in adolescent anxiety disorders.

As digital technologies become a way of life, young people are being exposed to environmental stressors that are uniquely associated with the 21st century. Inappropriate and over-use of technologies have been linked with anxiety disorders and are of concern for young people, their parents and educators (Australian Psychological Association [APA], 2017; Lawrence et al., 2016). Psychologists and others who work with young people are concerned that the hours spent online – and connected – expose teenagers to issues and dangers that their parents and teachers never faced. Teenagers are literally unable to ‘switch off’ from both positive and negative social interactions that they might have otherwise left behind at school; there are concerns about cyberbullying, inescapable social comparison, and this generation’s fear of missing out (APA, 2017; Goodwin, 2017; Lee, 2017).

Sensationalised and 24/7 media coverage of global terrorist events contribute to anxiety among young people, with spikes in fears after reports of events (Coughlan, 2018; Roy Morgan Research, 2016). Young people are as concerned about environmental issues as terrorism (Barrance, 2017; Deloitte, 2018) and are pessimistic about future employment prospects in an unpredictable and constantly changing labour market (Deloitte, 2018).

Significantly, the school environment, the pressure of achieving success at school, and the burden of scheduled extracurricular activities, are major stressors for young Australians (King, 2019). Bailey and colleagues (2016) found that, of those experiencing a ‘probable serious mental illness’, nearly 60% were concerned about study or school problems (p. 16) and young Australians do not fare well in OECD indicators of social and emotional wellbeing that relate to school. Australia ranks in the bottom third, worldwide, in areas such as perceptions of school pressure and feelings of belonging in school (ARACY, 2018, p. 6). Substantial bodies of literature demonstrate the important influence of students' schooling experiences on their social-emotional wellbeing and identify academic and social factors that detract from student mental health and wellbeing. These include the connection between low self-esteem and low achievement for students with learning difficulties (McArthur, Castles, Kohnen & Banales, 2016); a sense of not belonging within the school community (Joyce & Early, 2014); a sense of alienation from school (Hascher & Hagenauer, 2010); and feeling the stigma of 'otherness' due to difference and disability (Lalvani, 2015).

Neurodiverse students are more at risk of developing anxiety disorders than their typically developing peers but, in addition, they are not immune to the emotional turbulence or '21st century environmental stressors' experienced by other adolescents. Because these students are at a double disadvantage, identifying factors that lessen the risk of poor educational and life outcomes for this group of students is an important research focus.

### 1.2.3. The role of parents

> Parents continue to be a fundamental stakeholder in the education landscape and the only ones who can bring together the home and school life of Australia's children
>
> (Velegrinis, 2017).

Australian education policy and professional standards recognise the importance of the parent-school relationship in building school capacity to support the social-emotional wellbeing of children and adolescents (Australian Institute for Teaching and School Leadership [AITSL], 2017; DEEWR, 2017; Department of Education, 2013; Ministerial Council on Education, Employment, Training and Youth Affairs [MCEETYA], 2008).

Parent involvement in schools and engagement in education are terms used inconsistently and interchangeably, throughout the research literature on the parent-school relationship, to explain parents' direct participation in, and indirect support of, their child's schooling experience. Decades of research into the parent-school relationship has demonstrated that, while definitions are fluid, findings are consistent: effective parent-school partnerships promote positive learning and social-emotional outcomes for students (Epstein, 2010; Henderson, Mapp, Johnson & Davies, 2007; Hoover-Dempsey et al., 2005; Park & Holloway, 2013). Yet researchers have also raised the question of why it is so difficult, in practice, to develop effective partnerships between parents and schools (Mapp, 2017).

While there are several factors that characterise successful partnerships, they are all founded on effective communication on the issues that are important in that relationship (Isaacs, 1999; Keen, 2007). Meaningful discourse between parents and educators about the parent-school relationship implies a common understanding of the phenomena of parent involvement in schooling and parent engagement in education. Within the context of contemporary parenting, these phenomena might mean quite different things to parents and education professionals.

#### 1.2.3.1. Contemporary parenting

The concepts of parenting and parent participation at school are interrelated and can be understood from an ecological perspective (Bronfenbrenner, 1977, 1986, 1992): the parent-school relationship is not only affected by the immediate interactions between child and school and parent and school. Parents' personal values, beliefs and experiences determine their parenting behaviour, are affected by external social, technological and economic phenomena, and are positioned within constructions of what it means to be a 'good' parent (Miller, 2017; Mortimer & Larson, 2002; Sorin & Galloway, 2006).

The 21st century technological and social phenomena that impact on adolescent social-emotional wellbeing highlight their vulnerability and 'act upon the fears of adults and entrench 'protection'' in parenting behaviours (Sorin & Galloway, 2006, p. 6). Traditional parental concerns for their children's safety have been heightened in the 21st century by the saturation of print, online and televised media with stories of child predators, institutionalised child abuse, and random acts of terrorism and violence (Furedi, 2018; ReachOut Parents, 2016). Mackay (2005) argues that the 24/7 news cycle results in 'issues fatigue'– people turn away from bigger issues and become more protective of what they can control – their homes and their families. It has been argued that neo-liberal attitudes of self-reliance and responsibility have replaced trust in institutions (Barr et al., 2012; Vincent & Ball, 2007).

These concerns are shaped, encouraged and manipulated by the 21st century context – in a world dominated by online connectedness, parents are bombarded with scientific research and 'pseudo-scientific' opinion (Aarsand, 2014; Hopwood & Clerke, 2016). Manufacturers play to parent vulnerabilities and concerns about their child's educational and future employment opportunities and about their physical and online safety (Geinger Vandenbroeck & Roets, 2014). For many parents, and especially middle class parents, contemporary parenting is characterised by vigilant supervision where 'protection' has evolved into 'surveillance and control' (Sorin & Galloway, 2006, p. 6). Contemporary parenting is 'intensive parenting' (Wall, 2010, 2018) and is characterised by parents' increasing sense of responsibility for their child's present wellbeing and future success.

### 1.2.3.2. Parenting responses to 21st century environmental factors in adolescent anxiety

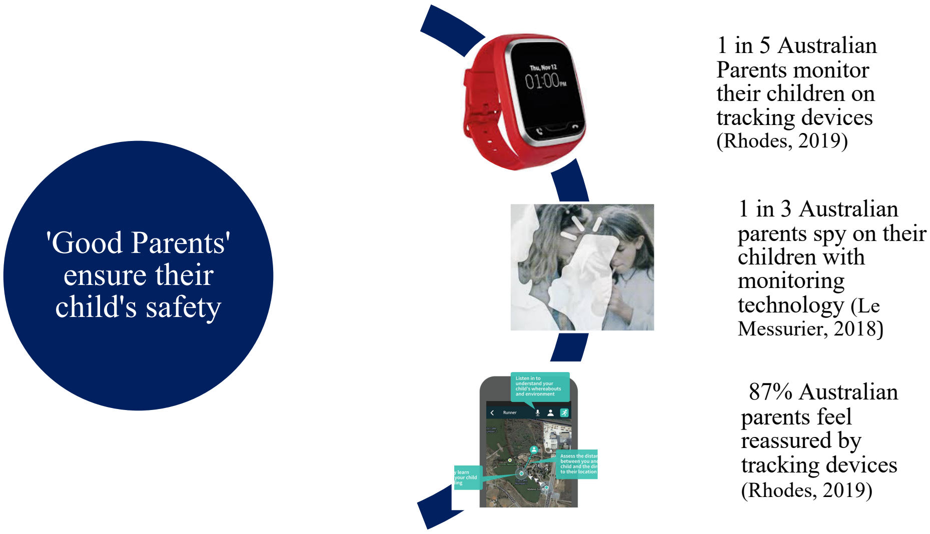

*Figure 1.1* How parents ensure their child's safety

Just as the internet presents adolescents with social and e-safety challenges, it has raised a host of new concerns for parents. In addition to their fears for their child's safety in the real world, they have to contend with the constantly shifting parameters of the online world. Blackman and Podesta (2017) suggest that, 'emerging technologies disrupt social norms' (p. 131) and as 'digital immigrants' (Prensky, 2001), most parents of ‘digital natives’ do not fully understand the social norms or ‘networked lives’ of their Post-Millennial adolescent (Boyd, 2014, p. *x*). Fears centre on the disruption of childhood innocence and teens’ capacity to enter a world beyond the reach and control of their parents (ReachOut Parents, 2016). This has created a culture of hypervigilant parenting, enabled by the capacities of 21st century technology, and encouraged by suggestive marketing that appeals to parents’ protective role. It is pertinent to consider whether this level of parental monitoring spills over into other areas of children’s lives, such as school, with potential impacts on parents’ perceived role in the parent-school relationship.

'How much enrichment is too much?'(Wedge, 2014)

'Tutoring has become the new baseline for 'good' parenting'(Edwards, 2019)

'The impact of school fees does hurt. It’s a large chunk of what we earn, but that’s what being a parent is' (in Bennett, 2019)

*Figure 1.2* How parents help their child reach their potential

Information technology has changed the way people access, create and apply knowledge. Global economies are increasingly driven by technological developments, which are based on knowledge production and dissemination and not limited by geography. Participation in the labour market of the 21st century, or ‘knowledge society’ (Hargreaves, 2003) is dependent on ‘information-processing skills and other high level cognitive and interpersonal skills’ and without those skills, Post-Millennials risk missing out (ABS, 2018; OECD, 2017b). 21st century assumptions around education are influenced by ‘persistently high’ rates of youth unemployment, a changing youth labour market, and concerns that existing Australian jobs will be replaced by Artificial Intelligence (International Labour Office, 2017; Reid, 2014). These assumptions also reflect an almost universal expectation in Australia that children will complete 13 years of school and that they will go on to tertiary study or Vocational Education Training (ABS, 2018; Coredata Research, 2018).

The ABS (2018b) indicates 31.4% of Australians aged 20-64 have attained a bachelor's degree or above. This is compared to 1991 (a year when all the study participants had either finished or were finishing school) when this applied to only 8% of Australians. In 2002 (the year the youngest child in this study was born), under 25% of school leavers were enrolled in higher education. By 2014, when the participants were making decisions around their children's high school, that figure had risen to 31% (Norton & Cakitaki, 2016). Parents of Post-Millennials encourage these aspirations as a means of 'future proofing' their child against an unpredictable vocational future through education and are influenced by an increasingly market-driven attitude to education (Robinson, 2018; Vincent & Ball, 2007).

Parents cannot avoid media reports of falling standards in literacy and numeracy in Australian Government schools – enrolling children in non-government schools, despite the financial hardship incurred, is viewed by many parents as an investment in their child's future (Bennett, 2019). Schools are sites of social reproduction, and the Australian middle-classes have traditionally sent their children to independent schools as a means of gaining or perpetuating social status. Now, enrolment at independent schools is viewed by the middle classes – 'old' and 'new' – as a means of securing their child's academic and vocational future (Butler, Ho & Vincent, 2017). The combined phenomena of this imperative to 'future-proof' and an increasing sense of parental responsibility for their child's overall development has seen a rise in what Lareau (2011) called 'concerted cultivation' – 'enrichment' activities, such as music, dance and language classes designed to 'round out' a child's education (Holloway & Pimlott-Wilson, 2014). In a climate of anxious parenting (Stearns, 2004), this intensive mode of parenting, dominated by middle-class values, is increasingly seen as the 'proper' way to raise a child (Romagnoli & Wall, 2012).

The 'relentlessness' of contemporary parenting (Miller, 2018), and a commonly felt sense of responsibility for, and investment in, their child's education might potentially impact parents' perceived role in the parent-school relationship. Intense scrutiny of, and criticism of, parenting practices, and the intrusion of experts, market forces, social commentators and government into the once private and domestic sphere of parenting complicates the parental role for contemporary parents and makes it difficult to understand how they should be involved in the various contexts of their child's life (Bagnall, Longhurst & Savage, 2003; Gilles, 2008; Lee, 2014).

Just as their children are not immune to 21st century environmental stressors, parents of neurodiverse adolescents are susceptible to the socio-cultural pressures on contemporary parenting. Understanding whether these factors affect their parenting experiences, and the parent-school relationship, will help contribute to a stronger understanding of the ways in which these parents are involved in their child's school.

#### 1.2.3.3. The role of parents and schools in addressing the social-emotional wellbeing of neurodiverse students

The role of parents in supporting neurodiverse adolescents with anxiety in a society that links child outcomes with parenting efforts and behaviours (Furedi, 2009) is extremely complex. Neurodevelopmental Disorders are still commonly unrecognised by teachers, the wider school community and even the child's own parents; and the learning, social and behavioural difficulties of neurodiverse children are regularly misunderstood or misattributed to poor parenting (Attwood, 2007; Barkley, 2013; Horton-Salway, 2011; Le Messurier, 2017).

Similarly, 'problem parents' are held responsible, by experts and social commentators alike, for child and adolescent anxiety (Rake, Grigg & Hannon, 2011). The message continues to be ambiguous for 'good' parents – protection and even overprotection are normal parental responses to their child's anxiety, but ones that will exacerbate that anxiety (Hudson & McKinnon, 2017). At the same time, research evidence points towards the importance of early intervention (McGorry, 2017) and the vital role of parents in identifying their child's issues and supporting their wellbeing (Rhodes, Measey, O'Hara & Hiscock, 2018).

As social-emotional difficulties are some of the most limiting and debilitating aspects of Neurodevelopmental Disorders, this underscores the need for parents to understand their child's anxiety, and its causes. Future wellbeing is strongly predicted by parental mental health literacy; that is, knowing how to recognise their child's mental health problems, how to provide support and where to access help

(Rhodes et al., 2018). Australian research indicates that although adolescents are using online mental health services more often, because of limited awareness of mental health issues and the continuing stigma attached to mental illness, they might have limited access, or are still reluctant to seek help in person (AIHW, 2016; McGorry, 2017). Removing the barriers to service access helps adolescents receive the best treatment options (Rickwood et al., 2019), but research indicates that, for those adolescents who do seek help, parents and friends are the first people they turn to for advice (Ivancic et al., 2018; Lubman et al., 2017). For those who do not seek help, the adults in their lives might be concerned but reluctant to get involved. Lubman and colleagues (2017) reason that, because adolescent anxiety is not always well understood, adults who might otherwise provide support may not know how or when to intervene. In a recent survey of Australian parents, one third of respondents were not sure that they even *should* intervene (Rhodes et al., 2018). While parents might intuitively know something is not quite right with their child, only 35% feel confident that they could recognise that their child is struggling with a mental health problem (Rhodes et al., 2018). Significantly, this lack of understanding cuts across cultural groups and levels of income and education.

Most Australian parents have either used or would use a website to find information about their child's mental health issues (ReachOut Parents, 2016) and numerous government and not-for-profit organisations have helped raise the profile of mental health and provide information for parents relevant to their teenager's problematic behaviours. Nevertheless, the majority of Australian parents want more information on how to identify social, emotional and behavioural problems and see teachers and school counsellors as critically important in bridging that information gap (Rhodes et al., 2018).

Schools are crucial contexts for adolescent development in general (Eccles & Roeser, 2011) and for social-emotional health and wellbeing more specifically (Department of Education, 2018c; Education Council, 2018). The Youth Mental Health Report 2017 (Bullot et al., 2017) strongly recommends that schools should 'provide evidence-based universal mental health prevention and intervention programs for young people' (p. 6). However, while Australian teachers acknowledge the importance of addressing adolescent mental health, they lack the time and resources to do so (Askell-Williams, Lawson & Dix, 2011; Bagshawe, 2015). Furthermore, schools and teaching bodies report that there are insufficient school counsellors to meet student needs or support the work of teachers (Evans, 2018; New South Wales Teachers' Federation, 2018). Importantly, Australian and international research has identified a 'mental health training gap' (Merz, 2017/2018, p.12; see also Ball et al., 2016) and educators consistently report that they lack confidence in their knowledge of, and ability to respond to, child mental health issues (Lahey, 2016; Mazzer & Rickwood, 2015; Scottish Association for Mental Health, 2018).

For these reasons, and because of the 'invisible' nature of their learning, social or behavioural difficulties, educators might misunderstand the ways in which neurodiverse children experience anxiety in the school setting. There is a need for research into how teachers and parents of neurodiverse children communicate on these important issues.

## 1.3. Investigating the parent-school relationship

Meaningful discourse between educators and parents of neurodiverse and anxious adolescents, about the parent-school relationship, implies shared interpretations of disability, diversity and inclusion and recognition of the ways in which neurodiverse children experience anxiety in the school setting. Whether all those involved in a child's education share a common understanding of these phenomena is an issue for educators as they seek to understand student needs and build effective relationships with their parents. It is also an issue for parents who want the best possible educational and social outcomes for their child. Parent voices are a necessary contribution to the 'unsettling conversations' around disability, diversity and inclusion (Pugach, Blanton & Florian, 2012).

Professional and parental expertise represent 'insider' and 'outsider' perspectives of education research and theory, of school spaces and systems, and of school quality and educational success. Professional and parental expertise also represent 'outsider' and 'insider' knowledge of the family system and the neurodiverse child (Pushor, 2017). These stances are potential sources of tension that might hinder effective communication between parents and educators, even when the common interest is the education and wellbeing of a child who is made anxious by the processes of learning and socialising that most take for granted.

Understanding the phenomenon of how and why parents of neurodiverse and anxious children participate in and support their child's education helps to address some of the questions around effective parent-school partnerships.

The current study's research approach, Interpretive Phenomenological Analysis (IPA), was selected as a means of exploring parents' interpretations of disability, diversity and inclusion and their motivations for participating in and supporting their child's education. IPA (Smith, 1996, 2004, 2011; Smith, Flowers & Larkin, 2009) is an interpretive approach to researching social phenomena with a focus on understanding the essential elements of individual's 'personal and social worlds' or 'lifeworlds' (Smith & Osborn, 2003, p. 53; see also Palmer, Larkin, de Visser & Fadden, 2010; Smith et al., 2009).

## 1.4. **Positioning the researcher: personal connection to the research**

IPA research requires the researcher to position themselves in relation to the research and to explore how previous experience and knowledge might result in preconceptions about the participants and the issue (Smith et al., 2009). Positioning the researcher also makes explicit the view that research is never value-free but is shaped by the researcher's experiences, opinions and worldview (Denzin & Lincoln, 2011).

My personal connection to the research derives from my personal parenting, teaching and research experiences and so provides both an 'insider' and 'outsider' perspective of the research topic.

### 1.4.1. Personal experience as a parent

As the parent of a child with an SLD, I have experience of supporting someone who feels alienated from school, and who experiences acute anxiety related to participating in normal schooling practices like assessment tasks and public speaking, sports carnivals and school camps. Until recently, our son's life has been dominated by the efforts of medical, mental health and allied health professionals to understand his issues and then to 'fix' them. We have tried numerous diets, conventional and alternate therapies and after-school tuition programs. I joined SPELD and went to all their information sessions. I joined parent support and information groups and went to all their morning teas and presentations. I too was determined to understand and 'fix' his issues.

Gradually, though, my perspective shifted and my current position on diversity was shaped by these ongoing efforts, as I saw how much they contributed to our son's anxiety. By pathologising his differences, by continually identifying the specific skills that he lacked in the classroom, and by constantly trying new ways to remediate that deficit we added to his feelings of otherness and anxiety. However, there appeared to be few opportunities, within the curriculum, to demonstrate his many strengths. He was continually encouraged to understand his Dyslexia from a perspective of difference not deficit, but he still felt constantly ashamed and self-conscious. He developed chronic social anxiety and we felt hopeless and distressed watching him struggle. We were caught in a conflicting position – the only way we could secure additional learning support was to have an IEP and Dyslexia was not the 'right' diagnosis. One paediatrician was inclined to an ASD diagnosis, another suggested that I had done all I could. Psychologists differed – did a learning issue cause his anxiety, or was it the other way around? Our son was also conflicted – he wanted to be included in the mainstream classroom and to feel the same as the other children, but he often felt safer in learning support and with others like him. A move to a new school with a different approach to learning, and a strong focus on inclusion wrought wonderful changes and a positive outlook for the future.

### 1.4.2. Personal experience as educator

My interest in the research topic was also informed by over twenty years' teaching experience, in both primary and secondary schools. I have witnessed the different cultures that exist in each sector and I understand the difficulty secondary teachers have in building the same kind of relationship with students and families that they may have experienced in primary school. The high school focus on discrete subject areas contributes to a siloed mentality that frequently separates departments and staffrooms and restricts the sharing of information and understanding of student needs.

When I started teaching, I knew nothing about SEN students– they attended the Special School next door. Until, in my first year, that school closed, and I found myself having to differentiate for students in my class with complex needs that I did not understand.

I knew almost nothing about mental health, and it took many years before I realised that the students in my class who were withdrawn or who acted out, might have been made anxious by the classroom environment, the curriculum or my teaching methods.

I spoke with parents at parent-teacher interviews. I thought the mums and dads who worked at the tuck-shop and coached sport were just helping, and it never occurred to me they were making a place for themselves in the life of the school. It was not until I became a parent myself that I really started to think about the parent-school relationship.

While more recent graduates are better prepared to understand the needs of diverse students, they are under increasing pressure to implement a far more rigid curriculum and deliver results on standardised assessments. I know from personal experience that individualising instruction is hard; understanding and managing the causes of challenging behaviour is hard; maintaining the enthusiasm inspired by professional development is hard. And dealing with parents like me, whose focus is the wellbeing of their child, and who want to know how you are doing on the first two points, is hard. While I have an 'insider' professional and parenting perspective, it is my perspective. I am an 'outsider' to every other parent's and teacher's experience, and I constantly needed to remind myself of that fact during this study.

### 1.4.3. Personal experience as researcher

My interest in the phenomenon of parent-school relationships also evolved from working as a research assistant on a project that examined successful inclusion practices for students and their families at a Queensland primary school, Forrester Hill State School. In that study, Abawi (2015) connected outward signs of school success at Forrester Hill – evidence of improved student learning outcomes and increased enrolment of SEN students – with a culture of inclusion that extended beyond the classroom and embraced parents and the wider community.

Abawi's (2015) study found that Forrester Hill extends an 'authentic welcome' (p. 48) to students who find school a challenging and often frightening place because of learning, social and behavioural difficulties. Parents noted the positive attitudes of staff towards helping their children overcome learning and social-emotional barriers to achievement through personalised and flexible learning environments, a commitment to educational differentiation and a focus on the explicit teaching of social and academic metacognition (Abawi, 2015).

During my involvement with the school, staff expressed concerns about what would happen next: their whole school focus had been on their students' holistic wellbeing and on 'wrapping' those students with support (Abawi, 2015, p. 53). They prepared careful hand-over plans for their neurodiverse Grade 7 students as they transitioned to high school but there were concerns about whether these students, and their parents, experienced the same degree of support and inclusion once they made that transition.

At the same time, it became apparent that effective strategies, structures and wider support services to sustain inclusion in schools needed to be clearly articulated. It was considered that a model for effective inclusion and transition for neurodiverse students would be of real benefit, and timely, because two cohorts of students would transition into secondary schools in 2015 when Year 7 became the first year of Junior Secondary in Queensland (Department of Education, 2018d).

## 1.5. Development of the research

Consequently, this research began as an investigation into how parents of neurodiverse students, with anxiety related to the school context, viewed their child's transition to high school and perceived their child's academic and social inclusion in this new setting. However, when I spoke with parents, they discussed that transition within the context of their child's schooling history through the metaphor of a 'journey' – the transition to high school was just another, and not necessarily the most significant, step in what had been, for each parent, a difficult journey.

As they told me their stories, they focused on describing their own 'parenting journey' of seeking answers about their child's difficulties in the school setting. They described their interactions with the professional staff at school, and with medical, mental health and allied health professionals, their constructions of self as parents and their hopes and fears for their child's future.

A requirement of IPA studies, and phenomenological research more generally, is the collection of 'rich' data via the 'detailed stories, thoughts and feelings' of participants (Smith et al., 2009, p. 57). Phenomenological researchers avoid imposing, on the participant's story, 'predetermined aspects of the phenomenon … assumed as significant' (Rich, Graham, Taket & Shelley, 2013, p.502). While the study retained its emphasis on student anxiety in the high school setting, the flexible nature of the research approach allowed me to respond to the participants' obvious concerns with conveying a bigger picture, resulting in a shift of the research focus (illustrated in Figure 3.3, Chapter 3). I became curious about the way these parents perceived their child's experiences and their parenting role, in relation to their neurodiverse child, and in relation to other aspects of their child's world.

## 1.6. Identification of research questions

In its final evolution, this qualitative study aimed to explore, through IPA, the lived experience of parents of neurodiverse adolescents who experience anxiety in the school setting. Specifically, the study aimed to explore these parents' lived experience of the parent-school relationship. Therefore, the study took as its central question:

‘How did the participants understand their neurodiverse child’s experiences in high school settings, and their role in supporting their child’s education?’

With this question in mind, I aimed to explore:

1. How the participants described and explained their child’s experiences at school.
2. How the participants described and explained their own experiences of supporting their child’s education.
3. How the participants experiences might be interpreted.
4. How principles, drawn from this interpretation, might contribute to current understandings of the inclusion of neurodiverse students, and of parent-school relationships.
5. How the study outcomes might contribute to better support practices for neurodiverse students and more effective parent-school partnerships.

## 1.7. Organisation of the thesis chapters

This chapter demonstrated that disability, diversity and inclusion are contested issues within the Australian educational context. It demonstrated that the social and emotional wellbeing of adolescents is a growing concern for educators and parents. Neurodiverse students, in particular, are at an increased risk for experiencing anxiety at school and mainstream teachers may find it difficult to understand and respond to these students’ complex needs. Exploring the lived experiences of neurodiverse adolescents, from their parents’ perspective, may help identify factors influencing the wellbeing of these students.

Parents of students with disabilities are often highly involved in their child’s schooling but, as neurodiverse students do not always fit within school guidelines for disability support, their parents may not enjoy the same ‘legitimate’ reasons to be involved in their child’s schooling. Collaborative parent-school relationships are necessary to effect two-way communication between home and classroom in general, and this is especially important for parents of neurodiverse and anxious children. However, effective parent-school partnerships are difficult to establish. Exploring the lived experiences of parents of neurodiverse adolescents may help identify barriers to parent-school partnerships from the perspective of this group of parents.

Chapter 2 contextualises the research problem against themes in the current research literature that are relevant to the lifeworlds of neurodiverse children. These include the social-emotional wellbeing of children and adolescents, disability and inclusion, school belonging and peer rejection. The literature discussion is organised from an ecological perspective (Bronfenbrenner, 1977, 1986, 1992) and also explores themes in the current research literature that are relevant to the lifeworlds of parents, including parent-school relationships and contemporary constructions of parenting.

Chapter 3 explains the research methodology and describes the research methods. This chapter connects the research problem, methodology and methods with Bronfenbrenner's theories of human development (1977, 1986, 2001) and Lakoff and Johnson's (1980/2003, 1999) Conceptual Metaphor Theory. In Chapter 4 the participants' lived experiences, which they shared in the interviews, are presented as abridged first-person narratives. The underlying meaning of these individual narratives are explored in Chapter 5 from a bioecological perspective (Bronfenbrenner, 1977, 1986, 2001a) and via the conceptual metaphors (Lakoff & Johnson, 1980/2003, 1999) that parents use to describe their lived experience. Chapter 6 examines the convergence and divergence of themes in the participants' lived experiences and places the discussion within the context of the relevant research literature. From the key shared experiences of the participants, Chapter 6 develops a set of principles around better support practices for neurodiverse students and more effective parent-school partnerships. Chapter 7 provides an overview of the study, addresses the central research question, and identifies recommendations for practice and suggestions for future research.

# CHAPTER 2: LITERATURE REVIEW

## 2.1. Introduction

The principle focus of the literature review in an IPA study is not so much about ‘gap spotting’ as about bounding the phenomenon (Smith et al., 2009). Hence, this chapter establishes the issues that underpin the participants’ stories presented in Chapter 4, and the researcher interpretation of these narratives in Chapters 5 and 6.

Chapter 1 argued the importance of understanding the lived experiences of parents of neurodiverse and anxious adolescents; with a specific focus on the parent-school relationship. The phenomenon of such relationships is complicated and multifaceted and, as such, is connected to a substantial and diverse research record. While an IPA study should not begin with a theoretical framework, it was apparent that the research surveyed in this study needed a structure that made sense in terms of the research phenomenon. Conroy (2003) identifies the difficulties inherent in reconciling the essentially linear account of the research project, that is a requirement in academic writing, with the reality of the process. She suggests that what the reader sees ‘belies the complexity, seamlessness, and flux inherent in interpretive research’ (p.38). The author must take the reader the most direct route, but the path is, in fact, spiralling and often circular. This is the best way to explain how an inductive study appears to begin with a theoretical outline.

At the point of data analysis in the study, several theoretical models were explored for their potential to explain the emerging concepts. These included Bronfenbrenner’s Ecological Systems Theory (EST) (1977, 1986, 2001a), Hoover-Dempsey and colleague’s Model of School Involvement (1997, 2005), Epstein’s Framework of Parent Involvement (1995) (Epstein & Salinas, 2004; Epstein et al., 2019); and Lareau’s Model of Concerted Cultivation (2002, 2011). Similarities exist between these theories – they explore the concept of family-school relationships; they explain parent involvement in their children’s education as a function of both intrinsic and extrinsic motivators; and they consider the social environments of home and school. However, EST provided the most convincing and comprehensive explanatory model for the participants’ experiences, the research questions, the concerns raised in Chapter 1, and the issues identified in Chapter 2.

Previous studies also demonstrate that organising the literature according to an ecological systems perspective is an effective way to limit and structure a discussion that is primarily interested in the social 'ecologies' of families and schools (Kamenopoulou, 2016; Odom et al., 2004). For these reasons, EST was retroactively applied to the literature review as an organising framework.

Bronfenbrenner (1977, 1986, 2001a) recognised that, for the purposes of empirical study on human development, the biopsychological characteristics of the individual cannot be separated from the reciprocal interactions between that individual and the settings in which they develop. It is equally awkward to write about these mutual influences as 'sub-sections' of a lived experience. However, in attempting to do this, this chapter explores the lifeworlds of neurodiverse adolescents, and the lifeworlds of their parents. Each section is further organised according to the systemic influences on their lives.

A considerable portion of the literature discussion was informed by relevant social policy frameworks and legislation, government and research institute reports, position papers and social commentary. While there are significant challenges associated with surveying this 'grey' literature (Paez, 2017), the continually changing landscape of issues relevant to adolescent wellbeing and parenting made it an invaluable indicator of current public sentiment and policy direction.

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## 2.2. **Placing the literature within a theoretical framework**

### 2.2.1. Ecological and bioecological systems theory

Bronfenbrenner's models of human development evolved from an original concern that many of the existing experimental designs observed 'the strange behavior of adolescents in strange situations with strange adults for the briefest possible periods of time' (Bronfenbrenner, 1977, p.513). He proposed an alternative, more 'ecologically valid' model, for examining human development which he named 'the ecology of human development' and defined as:

> *'the scientific study of the progressive, mutual accommodation, throughout the life span, between a growing human organism and the changing immediate environments in which it lives, as this process is affected by relations obtaining within and between these immediate settings, as well as the larger social contexts, both formal and informal, in which the settings are embedded'* [emphasis in original]
>
> (Bronfenbrenner, 1977, p.514)

This statement illustrates Bronfenbrenner's intention that any research enquiry into human development should have three emphases: the developing (or focal) individual, at a given point of development; the contexts and settings in which that individual develops, including immediate (proximate), and less proximate (distal) environments; and the reciprocal interactions between the individual and these contexts. As Bronfenbrenner's theory evolved, he refined his definition of each ecological 'system' but essentially these are the Microsystem, the Mesosystem, the Exosystem and the Macrosystem.

The *Microsystem* makes up the adolescent's immediate face-to-face environments in which she interacts with others and that directly affect her development. These settings, which include family, school, sport and medical, mental health and allied health contexts, each have particular social and structural characteristics, and in each the adolescent engages in activities specific to particular roles such as daughter, student, team member or patient (Bronfenbrenner, 1977, 1986, 1992).

The *Mesosystem* is, essentially, a 'system of microsystems' and describes the relationships and interactions between two or more settings, where both include the developing adolescent, such as interactions between his family and his school

(Bronfenbrenner, 1992 in Bronfenbrenner, 2005, p.148). The social interactions between family and school that 'bridge' two microsystems have been described as the 'school/family mesosystem' (Neal & Neal, 2013, p.730).

The *Exosystem* does not contain the developing adolescent, but she is indirectly influenced by social interactions between other actors within the exosystem and between the exosystem and her microsystems. The exosystem includes major institutions in society such as education and health authorities: in these contexts, within-system social interactions generate education and health policies that ultimately affect the adolescent. Between-system social interactions, such as between the Regional Director for Education and the adolescent's school Principal, affect the implementation of policy at the school level. This particular type of exosystem has been described as the 'education policy exosystem' (Neal & Neal, 2013, p.731).

One of the central themes in Bronfenbrenner's work is social and historical context (Darling, 2007), and the *Macrosystem* is made up of the broader social, demographic and cultural influences that provide a 'blueprint' for the society in which the adolescent lives (Bronfenbrenner, 1992 in Bronfenbrenner, 2005, p.150). As Bronfenbrenner (1977) explains, in each culture, schools and families follow patterns of structure, systems and functions. Some of these functions relate to political phenomena such as legislation. But most are less explicit and relate to the shared social attitudes and beliefs, resources and 'social address labels' such as social class that are common to a culture or subculture and that are passed down through its social institutions (Bronfenbrenner, 1992 in Bronfenbrenner, 2005, p.150).

Bronfenbrenner (1977) originally described these ecological environments as 'a nested arrangement of structures, each contained within the next' (Bronfenbrenner, 1977, p.515). Although this 'nested' arrangement of ecological systems is most commonly represented as concentric circles, this model does not demonstrate Bronfenbrenner's intended focus on *within and between* setting interactions. That is, how a change in one system affects the other systems in which the adolescent develops (Rosa & Tudge, 2013; Tudge, Mokrova, Hatfield & Karnik, 2009; Tudge et al., 2016).

Throughout the 1980's and 1990's Bronfenbrenner refined the ecological systems model by adding the dimensions of time and individual biology and heritability to the model, and by more clearly defining the interactions within and between the individual's proximal and distal systems:

*The Chronosystem* (Bronfenbrenner, 1986) represents the effect of time, change and continuity on the developing adolescent: at the level of his individual life-transitions, at the broader level of his life-course and reflecting the historical epoch in which he lives. In terms of this chapter's organisation, the chronosystem is represented across the lifeworlds of adolescents (in their age/stage development and school transitions) and parents (in terms of the period influences on parenting).

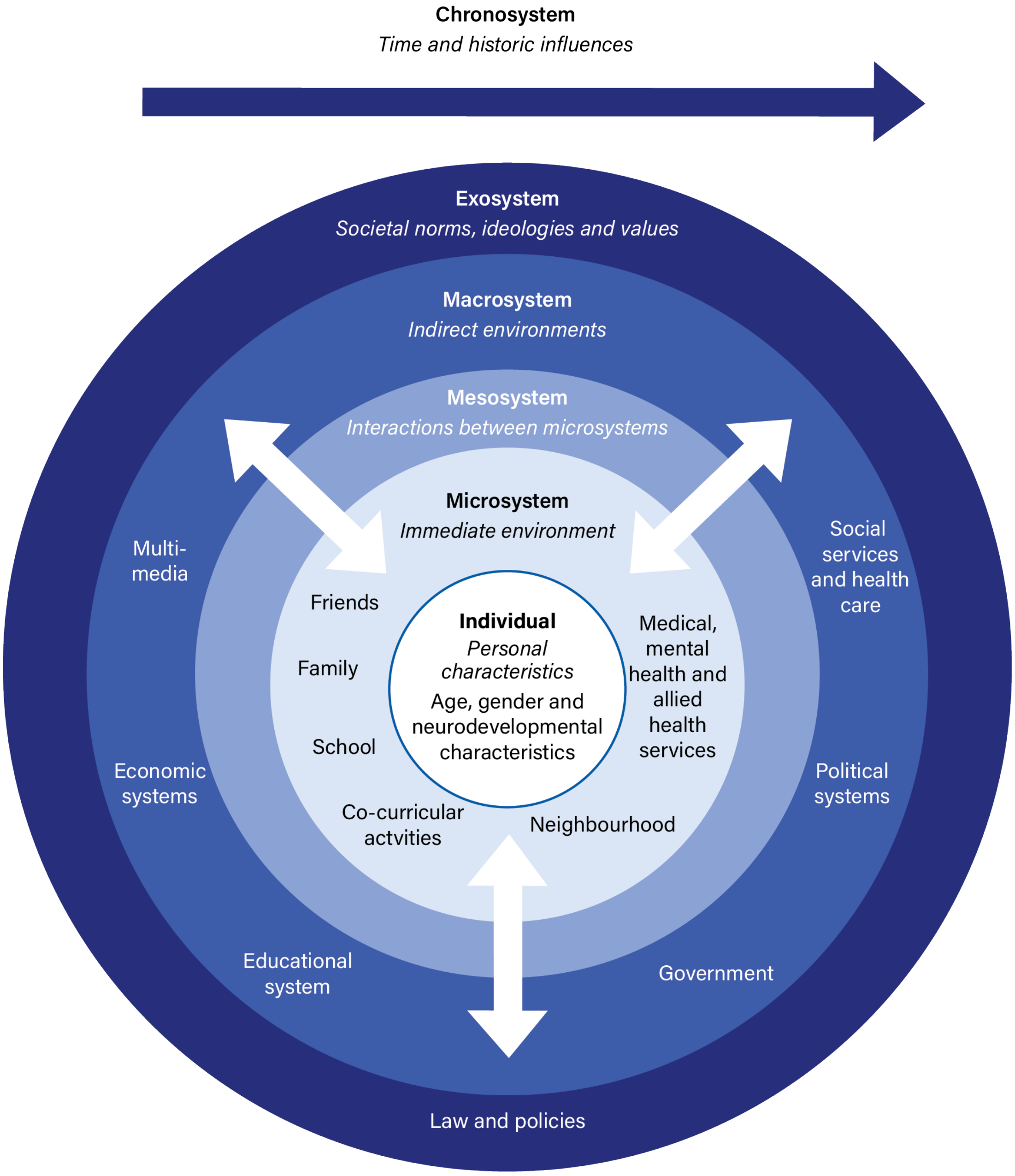
*Bioecological Systems Theory* (Bronfenbrenner, 2001a; Bronfenbrenner & Ceci, 1994; Bronfenbrenner& Evans, 2000). The dimensions of individual biology and heritability are represented in the Bioecological Systems model, which focuses on the interaction between the 'active, evolving biopsychological human organism and the persons, objects, and symbols in its immediate environment' (Bronfenbrenner & Ceci, 1994, p.572). That is, Bronfenbrenner stresses the *mutual* influence of individual and heritable genetic traits, environment and life experiences on a developing individual's physical, intellectual and emotional development. He theorised that an individual's genetic potential or heritability is only realised through the 'reciprocal interactions' that occur within the microsystem, which Bronfenbrenner called *proximal processes* and which he claimed, 'function as the engines of development' (Bronfenbrenner & Evans, 2000, p.118).

*Ecological niches* (1992). Bronfenbrenner's refinement of EST focused on the person-context interaction which jointly accounted for both person and environment characteristics. He explained that this design allowed for the identification of ecological niches; 'particular regions in the environment that are favorable or unfavorable to the development of individuals with particular personal characteristics' (in Bronfenbrenner, 2005, p.111).

*Person-Process-Context-Time*: The effect of proximal processes on the person, within-context and over time. Bronfenbrenner and Evans (2000) clarified that the effect of proximal processes depends on the interaction between the developing adolescent's individual characteristics, the resources available in the environmental contexts, the degree of continuity and change in the time period over which these processes occur and the historical period in which development occurs.

Bronfenbrenner and Ceci (1994) proposed that positive developmental outcomes are more likely when proximal processes occur over extended periods of time in ‘advantaged and stable environments than in those that are impoverished or disorganized’ (p.577). For example, literacy outcomes are not just dependent on an adolescent’s heritable characteristics but on the availability of resources, quality and continuity of instruction across an extended time frame; the stability of her home environment; and the social attitudes to literacy within her culture and community.

These within and between system interactions are illustrated in Figure 2.1.



| Exosystem | Macrosystem | Mesosystem | Microsystem | Individual |
|---|---|---|---|---|
| Systems that influence the individual indirectly through microsystems. | Social ideologies and values of a culture. | Connections between systems and microsystems. | Direct interaction in activities, roles and relations with others and objects. | Influence of age, gender and neuro-developmental characteristcs |

*Figure 2.1* Adapted from Bronfenbrenner’s (2001a) Bio-ecological Model of Human Development

## 2.3. **The adolescent's macrosystem**

### 2.3.1. Student mental health and wellbeing

The adolescent's macrosystem includes shared understandings of, and social attitudes to wellbeing, disability and inclusion in Australian society. Chapter 1 outlined concerns for the mental health and wellbeing of young Australians, and the long-term implications of mental *ill* health. Current research initiatives and social policy aimed at addressing these concerns are characterised by an attempt to define *well*being (AIHW, 2018; Bailey et al., 2016). Absence of wellbeing is relatively easy to identify via the symptoms of psychological distress (Bullot et al., 2017) but defining the elements of positive psychological states is more ambiguous (Dodge, Daly, Huyton & Sanders, 2012; Hamilton & Redmond, 2010). The difficulty lies in deconstructing the monistic view of wellbeing, which is often equated to 'happiness', when conceptualising 'what makes life worthwhile' is more complicated (Chodkeiwicz & Boyle, 2016; Rath, Harter & Harter, 2010; Seligman, 2011; Seligman & Csikszentmihalyi, 2000).

While there are no definitive and universal understandings of 'wellbeing', recent Australian research depicts it as a multidisciplinary concept that includes objective domains such as physical health, material wealth and housing, and the more subjective domains of emotional, psychological, social and spiritual wellbeing (Redmond et al., 2016; Svane, Evans & Carter, 2019; The Centre for Adolescent Health, Murdoch Children's Research Institute [MCRI], 2018b). Additionally, attention has shifted from understanding wellbeing as simply a positive emotional state to seeing it in terms of how well an individual is actually functioning (Chodkeiwicz & Boyle, 2016; Wallace, Holloway, Woods, Malloy & Rose, 2011).

Government-sponsored research is increasingly interested in subjective wellbeing, representing a shift from viewing the population's welfare in terms of economic prosperity towards broader concerns about the holistic quality of people's lives and what constitutes 'the good life' (ARACY, 2018; Lamb & Huo, 2017; Wallace et al., 2011). Subjective wellbeing is understood as the dynamic interaction between an individual and the environments in which they live, work and socialise. These interactions occur across the lifespan and are influenced by the individual's developmental stage (Education Services Australia, 2018; Hamilton & Redmond, 2010). As a domain of general wellbeing, social and emotional wellbeing (SEWB) can be described as the 'experience of positive behaviours and emotions, as well as how the individual adapts and copes with daily challenges (through resilience and coping skills) while leading a fulfilling life' (AIHW, 2018, Indicator 18).

### 2.3.2. The social emotional wellbeing of young people

Interest in the SEWB of young people is based on the critical importance of childhood and adolescence in lifespan development (ARACY, 2018; Davison, Nagel & Singh, 2017). If wellbeing is understood in terms of a continuum, current research has a positive focus on what helps young people to thrive and flourish (Seligman, 2011) and this requires a consistent understanding of child and adolescent SEWB (E.S.A, 2018).

Although there is no common set of child wellbeing indicators in Australia (Hamilton & Redmond, 2010; Redmond et al., 2016), ARACY's (2018) 'report card' on the SEWB of Australia's young people consolidates objective and subjective measures of wellbeing into six overarching domains:

- Loved and safe
- Material basics
- Health
- Learning
- Participating
- Positive sense of identity and culture.

Each domain includes indicators of wellbeing – statistical measures that add up to a composite picture of 'what wellbeing looks like' for young Australians (ARACY, 2013). The Australian Child Wellbeing Project derived its broad conception of wellbeing from the issues that adolescents and children identified as important for the 'good life'. Four domains emerged:

- Subjective health
- Family cohesion
- School engagement and relationship with peers, plus a fifth dimension that cut across these domains
- Life satisfaction (Redmond et al., 2016, p.205).

The common factor among these indicators and domains is the socially situated nature of child and adolescent SEWB (ESA, 2018; Hamilton & Redmond, 2010).

From an ecological perspective, the SEWB of children and adolescents can be seen as ‘multifaceted’ and dependent on their interactions within and between the environments in which they live, learn and socialise (Ben-Arieh, Casas, Frones & Corbin, 2014; see also AIHW, 2018, Indicator 18; Redmond et al., 2016). Klocke, Clair and Bradshaw (2014) compared surveys of young people’s wellbeing across 43 countries and found that interactions at the microsystemic level (child-school and child-family) and mesosystemic level (interactions between school and family) have the most influence. Macrosystemic factors such as national GDP and youth unemployment have little direct impact. In other words, the immediate environments of home and school appear to have the most influence on the subjective wellbeing of children and adolescents.

### 2.3.3. School-related SEWB

A substantial national and international research effort, producing largely quantitative data, has been directed towards understanding the environmental factors that threaten or protect young people’s SEWB in home and school environments (see Fuller, Pullen, Swabey, Wicking & Wicking, 2017; Furber et al., 2015; Greenberg, Domitrovich, & Bumbarger, 2001; Guy et al., 2016 and others). Researchers have begun to recognise the value of asking young people what is important to them (Powell, Graham, Fitzgerald, Thomas & White, 2018; Redmond et al., 2016), reflecting a growing interest in young people’s well*being* or current SEWB. This is in contrast to conceptions of well*becoming* that emphasise the risk and protective factors involved in a young person’s future wellbeing and that are driven by concerns for the impact of low wellbeing on national economic productivity (ARACY, 2014). Increasingly, wellbeing in childhood and adolescence, in and of itself, is considered as important as the potential impacts on their future development (Ben-Arieh, 2008; Mason & Danby, 2011; Tisdall, 2015). Furthermore, a growing body of qualitative research is interested in young people's perceptions of their wellbeing (Dex & Hollingworth, 2012; Priest, Thompson, Mackean, Baker & Waters, 2017; Slee & Skrzypiec, 2016).

School is a critical context for the social and emotional development of young people, so it is unsurprising that their overall SEWB is strongly associated with school-related factors (House of Commons, 2017; Mazzer & Rickwood, 2015; UNESCO, 2015); and the right 'fit' between environment and developmental stage (Eccles et al., 1993; Eccles & Roeser, 2010, 2011; Tian, Chen & Huebner, 2014; Roeser, Eccles & Sameroff, 2000).

### 2.3.4. The wellbeing of SEN students

Humphrey, Lendrum, Barlow, Wigelsworth and Squires (2013) observe that SEN students are 'widely considered to be the most vulnerable group of learners' (p. 1210) but until recently, their perspective has rarely been sought in conceptualising school-related SEWB (Redmond et al., 2016). Foley, Blackmore, Girdler and O'Donnell (2012) asked children and adolescents with SEN to explain their personal understanding of 'the good life'. Six key themes were identified, including 'the importance of good friends; family factors; anxiety relating to performance at school; coping strategies and resilience; and personal growth and development' (p.379). The authors emphasise that this group overwhelmingly conceptualised school-related SEWB as the ability to fully participate, either in friendship groups or in the classroom. This is supported by Robinson and Truscott's (2014) review of the research on issues relevant to young people with SEN, which concludes that the most important contributor to their wellbeing is a sense of belonging and connectedness. More pertinent to the current study, a growing body of qualitative research has explored school-related wellbeing from the perspective of neurodiverse young people (Goodall, 2018; Leitao et al., 2017; Sproston, Sedgewick & Crane, 2017; Weiner & Daniels, 2016) and young people with mental health difficulties (Holdsworth &

Blanchard, 2006). For this group of students, a sense of belonging is a key factor in their SEWB.

### 2.3.5. Conceptions of disability and social inclusion

Analysis of data from the *Longitudinal Study of Australian Children* (LSAC) (AIFS, 2019), along with the findings of other major Australian studies, indicate that while young people with disabilities aspire to 'the good life', they are more than twice as likely as their peers to have low levels of physical, material and social emotional wellbeing (ARACY, 2018; Emerson, Honey & Llewellyn, 2008; Redmond et al., 2016). Emerson, Llewellyn, Honey and Kauiki (2012a) argue that the negative association between low wellbeing and disability should not be viewed as 'an inevitable consequence of peoples' impairments' (p. 181). Rather, they argue, it is the *social* consequences of disability that contribute to low wellbeing – there is a reciprocal influence between health constraints (including mental health), education, employment opportunities and material poverty and social isolation. The authors emphasise that, while there are negative and limiting aspects to disability per se, the impacts on young people's wellbeing largely arise from environmental barriers to social participation.

The concept that wellbeing, disability and environment are dynamically interrelated is consistent with the World Health Organization's (2011) revised definition of disability as 'an umbrella term for impairments, activity limitations and participation restrictions' (p.2) that arise from the 'interactions between health conditions (diseases, disorders and injuries) and contextual factors' (p. 10). The Convention on the Rights of Persons with Disabilities (CRPD) (2006) adds that 'disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others' (United Nations General Assembly, 2006, Preamble .5). These conceptions of disability are consistent with contemporary ecological and holistic explanations for physical and mental health and wellbeing.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013) classifies and defines the diagnostic criteria for mental disorders that begin in childhood and persist through the lifespan. These include Neurodevelopmental

Disorders such as ASD, Attention Deficit Disorders (including ADHD) and SLDs (including Dyslexia). The DSM-5 also defines the diagnostic criteria for mental health disorders such as anxiety and depressive disorders, specific phobias and compulsive disorders which either co-exist with, or are inherent in Neurodevelopmental Disorders (APA, 2013). Although the term 'mental disorder' logically contrasts between bodily- and brain- situated disorders, there is a strong stigma attached to the association between 'disorder' with disease and pathological conditions (Kaushik, Kostaki & Kyriakopoulos, 2016; Wright, Jorm & McKinnon, 2011)

The negative social perceptions and processes of stigma are central to the lived experience of children and adolescents with disabilities (United Nations Children's Fund [UNICEF], 2013) and mental health disorders (COAG, 2017; DeLuca, 2019). Kaushik and colleagues (2016) reviewed the literature on stigma and demonstrate that young people with mental illness experience 'significant, multifaceted and universal' stigma (p. 491).They also provide evidence that young peoples' attitudes towards mental illness are changing; media representations of mental health have helped normalise mental health disorders and, in the same way, neurodiverse people are being 'normalised' on television and in film (Alexander & Black, 2018). Questioning the discourse around disability and mental illness challenges the components of stigma – the negative stereotypes, labels, discrimination and prejudice (Hinshaw, 2005) that separate, 'discredit' and 'taint' the stigmatised (Link & Phelan, 2001).

From the perspective of the individuals who have these DSM-5 diagnostic characteristics, and from the perspective of their families and many education, medical and mental health professionals, these traits are increasingly understood as different abilities, not disorders (Jaarsma & Welin, 2012; Kapp, Gillespie-Lynch, Sherman & Hutman, 2013; Russell & Norwich, 2012). A groundswell of 'neurodiversity activism' from neurodiverse individuals and their families aims to show that this is their 'normal'; but also aims to highlight the issues of being 'differently abled'. They highlight that the lived challenges and psychological distress experienced by these individuals is socially, not biologically, situated (Armstrong, 2017; Hughes, 2016; Kras, 2010; Silberman, 2012); and that there are ethical issues around the ‘pathologising’ of neurological difference (Pellicano & Stears, 2011).

The work of anthropologists Rayna Rapp and Faye Ginsburg illustrates this ecological explanation of ‘disability’ and is positioned in the authors’ own lived experience as parents of ‘differently abled’ children. Their work investigates the ‘worlding’ of disability (Rapp & Ginsburg, 2017) – the gamut of conceptions and lived experiences of ‘disability’ and Neurodevelopmental ‘Disorders’ (Ginsburg & Rapp, 2013). They discuss the work of biomedical researchers who contribute to the neuroscientific discourse around ADHD and SLDs (Rapp & Ginsburg, 2001). They tell the stories of parents of children with physical and neurocognitive ‘disability’ whose lives revolve around negotiating the socially imposed barriers to participation in education and society (Rapp, 2011, 2015). And they explore the artistic and political activism of ‘differently abled’ and neurodiverse people like David Flink who are renegotiating the meaning of disability and difference (Rapp & Ginsburg, 2017) and showing neurodiverse young people ‘how to be their own best advocates as they embrace – and capitalise on – their unique ways of looking at the world’ (Eye to Eye, 2019).

The re-imagining of ‘disabled’ to ‘differently abled’ continues the longstanding debate on defining physical and psychological impairments and disabilities. Mike Oliver picked up the discourse of earlier disability activists, such as The Disabled People's International, and developed these into the Social Model of Disability (1990), which became the ‘vehicle for developing a collective disability consciousness’ (Oliver, 2013, p. 1024). This was instrumental in illustrating the lived experience of people with disabilities and in re-defining ‘disability’ in terms of the social barriers to participation (Oliver, 1990). Criticisms, acknowledged by Oliver, of the social model from within the medical research and disability community suggest that, first, it portrays disabled people as ‘one unitary group’ rather than a diverse, complex array of people; and second, that the model does not properly recognise that impairment is grounded in real physical and emotional limitations (Oliver, 2013, p.1025).

The first criticism could be applied to the language of contemporary Australian media, education policy and research literature. Within these areas, ‘children and/or adolescents with disabilities' is a common term that fails to represent the complex interactions between specific impairment, social restriction and resultant ill-being (Maxey & Beckert, 2016), or the individual's specific needs (Matthews, 2009). Disability categories inadequately explain the 'double disability' and added burden of the mental health disorders associated with Neurodevelopmental Disorders (Dix, 2011). While the NCCD addresses this issue to some extent, it is still based on broad categories of disability (Iacono et al., 2019) and there is limited data, at a national level, to reflect the diversity of differently abled children, that indicates how many young Australians live with specific 'disabilities', or that illustrates the precise manner in which their lives are affected (Cologon, 2013; Education Council, 2018). Currently, there is no systematic identification of exactly which children have which 'invisible disabilities' (Deloitte, 2017).

The second criticism is illustrated by the challenges faced by students with disabilities in school settings: it is evident that while there are social and attitudinal barriers imposed by students' 'disabilities' (Iacono et al., 2019; McMaugh, 2011), impairments present real limitations to learning and participation in mainstream classrooms (Dix, 2011). Effective inclusion of students with disabilities means finding a way to 'respect as well as respond to human differences' (Florian & Black-Hawkins, 2011, p. 815) and acknowledge that impairments 'both enrich and restrict' life experiences (Reindal, 2008, p. 144). These issues, and the absence of a common language around 'disability', point to the difficulties in conceptualising inclusion (Forlin et al., 2013; Humphrey et al., 2013; Nilholm & Görranson, 2017). This is especially true for neurodiverse students where there are inconsistencies, within the Australian context, in identifying or defining their 'disability'.

In their review of the literature on inclusion, Nilholm and Görranson (2017) identified two main positions on including SEN students in mainstream classrooms. From the perspective of 'education for all', including all students, all the time is part of the broader process of democracy (Ainscow, 2013; Slee, 2009). Another perspective, espoused by most Australian education authorities states that inclusion benefits all students (Department of Education, 2018b; Forlin et al., 2013; OECD, 2012), but is less clear on what this looks like in practice. In other words, inclusion, and how it should be achieved, are contentious issues (Abawi, 2015; Hyde, 2014;

Mann, Cuskelly & Moni, 2018). There are conceptual differences between 'inclusive education' (Cologon, 2013; Slee, 2009), 'inclusive pedagogies' (Abawi & Oliver, 2013; Cochran-Smith & Dudley-Marling, 2012; Florian, 2014) and 'inclusive practices' (Anderson & Boyle, 2015; Graham, Proctor & Dixon, 2016).

'Inclusive education' originated in the concerns of special needs educators about systemic issues with special education – the segregation of SEN students in special schools and institutions; the overrepresentation of minority group students; and the stigmatising effects of labelling based in medical discourse (Collins, 2013; Florian, 2014; Lauchlan & Boyle, 2007; Slee, Corcoran & Best, 2019). This approach views inclusion as the normalisation of difference and as more than a 'disability' issue (Ainscow, Booth & Dyson, 2006; Forlin et al., 2013). It is based on recognition that, within the 21st century classroom, learning, social and behavioural differences sit alongside racial, ethnic and socio-economic diversity (Foreman, 2014; Slee, 2011).

'Inclusive pedagogies' are the school-wide and classroom structures and processes that help all students to participate, and that address the needs of all learners (UNICEF, 2012). Inclusive pedagogies focus on the delivery of a quality education to all students within the school community (Anderson & Boyle, 2015) through approaches such as the Universal Design for Learning framework (CAST, 2019); the Quality teacher Framework (NSW Department of Education and training, 2008); and the Productive Pedagogies Model (Lingard, Hayes & Mills, 2003).

'Inclusive practices' accommodate individual difference, within the mainstream classroom, by adjusting curriculum content, teaching approaches, and assessment methods to meet individual needs. This is the most common form of inclusion in mainstream schools and much depends on teacher quality. It can amount to 'inclusion as shared space' (Salmon, 2013) if the student is present but simply integrated into the classroom. Additional support requires the identification and classification of impairment and is based on a medical model of disability; that is, difference is made to matter if a student is to receive the assistance they need to participate and achieve (Collins, 2013). Numerous studies indicate that focusing on the students' disability serves to emphasise their 'otherness' or difference from those privileged as 'normal' (Lalvani, 2012; Norwich, 2013). The effects of labelling or categorisation are contested and inconclusive because while labels can ensure assistance, they can inadvertently stigmatise the student receiving additional support (Gibbs & Elliott, 2015; Gutshall, 2013; Ohan, Visser, Strain, & Allen, 2011; Salmon, 2013).

Hyde (2014) proposes that the most important conception of inclusion is an individual one: identifying what an individual student needs to feel included through their sense of emotional, social and academic connection to the whole school and classroom environment. Salmon (2013) describes this as ‘inclusion as shared experience’ as the student’s experience encourages a sense of belonging and connection. This type of inclusion – in society and in schools – is fundamental to the wellbeing of ‘differently abled’ young people (ACARA, 2012; Children with Disability Australia, 2015; Cologon, 2013; Robinson & Truscott, 2014; Urbis, 2015).

## 2.4. The policy exosystem

The mental health and wellbeing of all students depends on the degree to which they are able to participate, achieve and connect with others in the school environment (ESA, 2018; Noble, Wyatt, McGrath, Roffey & Rowling, 2008). To make this happen, and to create inclusive and supportive learning communities, schools must be guided by clear and evidence-based policies that are responsive to the needs and concerns of stakeholders (Education Council, 2018; Victorian Council of Social Service, 2016). The policy exosystem includes the systemic influences on, or legislative ‘drivers’ of, inclusion and wellbeing in Australian schools that reflect the state’s vision, purpose and values (Foreman, 2015; Neal & Neal, 2013). The levels of that exosystem working together to achieve inclusion and wellbeing include international agreements, national and state legislation and policies, and curriculum frameworks.

### 2.4.1. International agreements and initiatives

Within the United Nations’ community, education for all is a universally recognised right and objective, if not a universally realised practice. UNESCO concedes that its global aim of an ‘inclusive education for all’ by 2030 is ‘ambitious’ (UNESCO, 2015, 2017). Nevertheless, the Australian Government has actively committed to developing an inclusive society and an equitable, quality education system through its support of major international human rights and education agreements (Australian

Human Rights Commission [AHRC], 2018; Department of Foreign Affairs and Trade, 2019). These include the Salamanca Statement and Framework for Action on Special Needs Education (Salamanca Agreement) (UNESCO, 1994) and the Global Education 2030 Agenda (UNESCO, 2015), which commit member states to advancing equity and inclusion in and through education; and the CRPD, which outlines the signatories' obligations to ensure equal opportunities and social inclusion for people with disabilities (Office of High Commissioner Human Rights [OHCHR], 1996/2019). By upholding the United Nation's Convention on the Rights of the Child, Australian governments have agreed to protect children's basic rights to life, survival and development, and also to act in the best interests of the child, to respect children's views, and to ensure their lives are free from discrimination (UNICEF, 2006).

### 2.4.2. National and state legislation and policies

As a signatory to these agreements, the Australian Government exercises its obligation to protect and promote human rights, ensure equality before the law, remove existing barriers to social participation and prohibit discriminatory practices under the *Disability Discrimination Act 1992* (DDA) (Australian Government, 2013). The legislative obligations of educators towards the inclusion of SEN students under the DDA are clarified through the *Disability Standards for Education 2005* (Disability Standards) (DEEWR, 2012) and, together, these provide the overarching framework for state and territory inclusive education policies (DET & E.S.A, 2019). As the Disability Standards apply universally within Australian schools, this framework ensures that SEN students have a right to enrol *on the same basis* [emphasis added] as their peers, and without discrimination (DET & E.S.A, 2019).

The federated nature of the Australian context means that, subject to national legislation and curriculum frameworks, education and schools are primarily state and territory responsibilities. In Queensland, the direction of education is outlined in *Every Student Succeeding – State Schools Strategy 2019-2023* (Department of Education, 2019b), within which the *P–12 Curriculum, Assessment and Reporting Framework* (P–12 CARF) and the *Inclusive Education Policy* guide the provision of what aims to be an 'inclusive education' for all students, including those with special educational needs (Department of Education, 2018a). An extensive review into these policies identified that, amongst the broad cohort of interviewees and submissions, the term 'inclusive' was not always clearly understood, interpreted or applied (Deloitte, 2017, p. iv). In fact, only 62% of Queensland teachers were 'fully aware' of the DDA or Disability Standards (Deloitte, 2017, p. 59). The Department's response, in the *Inclusive Education Policy Statement,* recognises the 'evolving' nature of inclusion; acknowledges current discrepancies between inclusion as a concept and inclusion as a practice; and concedes that Queensland state schools are 'at different stages of their journey towards adopting inclusive education' (Department of Education, 2018b).

Under the Salamanca Agreement (1994), Australia has committed to including 'all children regardless of individual differences or difficulties' in 'regular schools' (p. ix). Education policy in Australia is fundamentally orientated towards UNESCO's aims of celebrating difference and supporting individual needs (Forlin et al., 2013; Hardy & Woodcock, 2015; Woodcock & Reupert, 2016) and these aims are appropriate to the development of positive student mental health and wellbeing (Jarvis, 2011; Jarvis, Pill & Noble, 2017; McMillan & Jarvis, 2013). However, the language of the Disability Standards moderates the power of the Salamanca Agreement (1994), and the capacity for *all* students to access and effectively participate in education on the same basis (Deloitte, 2017; Urbis, 2015). Although all students have a right to attend any State school and, while schools must provide *reasonable adjustments* to the school environment, curriculum and teaching practices, there is a proviso that schools must not incur *unjustifiable hardship* [emphases added] (DEEWR, 2012, 3.4 p. 14). A recent review found the Standards allow education authorities to exercise considerable discretion in what they deem to be reasonable or unjustifiable (DET, 2015a; Urbis, 2015, p. ii).

Anderson and Boyle (2015) point out that there are no consistent national measures of inclusive education: as the Standards imply, the everyday arrangements for inclusion are a state and school responsibility and, because of the confusion around defining inclusion, are not consistent across Australia (Abawi & Oliver, 2013; Forlin et al, 2013; Urbis, 2015). Savage and O'Connor (2018) describe this as a '*partial decoupling* of policy development and implementation' common to OECD nations [emphasis in original] (p. 3) and there is wide-spread evidence of such policy-practice gaps within which schools have developed their own ‘inclusion’ practices. Such practices frequently discriminate against or exclude students, and SEN students and their parents have reported extensive gatekeeping practices that discourage or deny full enrolment. These include suggestions that other schools might be better suited to a child’s needs or blunt refusals to adjust environment, teaching or learning provisions on the grounds of resource limitations (Bourke-Taylor, Howie & Law, 2010; de Bruin, Graham, Poed & Spandagou, 2018; Graham et al., 2016; Iocano et al., 2019; Poed, Cologon & Jackson, 2017).

In Australia it is common for inclusion practices to occur on a continuum. In Queensland, students with high levels of need usually attend Special Schools or Special Education Units attached to mainstream schools. Despite the segregated nature of these settings, these are considered as pragmatic responses by education authorities to student needs within existing systems and structures (Deloitte, 2017; Department of Education, 2018a). While recognising the welcoming environment of Special Education Units, and the expertise of Special Education staff, disability advocacy groups believe these settings unnecessarily separate high needs students from their peers (Queensland Parents for People with a Disability, 2011) and some educators see this as inconsistent with the philosophical aim of full inclusion in mainstream schools (Cologon, 2013; Florian & Rouse, 2009; Slee, 2009).

All other SEN students are included, to varying degrees, and with varying levels of support, in mainstream classes. However, submissions to national and state reviews of disability policy and education practices indicate that the most common experience for SEN students is *integration* into mainstream classrooms without, or with inadequate, adjustment to their needs (DSS, 2009; Deloitte, 2017; Urbis, 2015; The Commission, 2017). Arguably, this gap between the rhetoric of inclusion and widespread inconsistences in practice reflects the broader social assumptions and attitudes towards ability and disability (Jindal-Snape, Douglas, Topping, Kerr & Smith, 2005; Norwich, 2013; Reiser, 2012; Watson & Boman, 2005).

### 2.4.3. National priorities for inclusive education

In the Australian context, the Commonwealth sets the big picture agenda for curriculum, assessment and professional standards for educators in an increasingly centralised and uniform context (Hyde, 2014; Rose, Low-Choya, Singh & Vasco, 2018). As an example, the Australian Curriculum 2.0, a national Foundation to Year 10 framework, embodies the principles of The Melbourne Declaration on Educational Goals for Young Australians (2008) (ACARA, 2019a). This is the most recent statement, by COAG on the importance of education to the wellbeing of its young people and to their well-becoming, that is, the nation's future prosperity and social cohesion. Its two main educational goals are:

- That Australian schooling will promote 'equity and excellence' through provision of a quality education, free from discrimination (MCEETYA, 2008, p. 6).

- That all young Australians 'will become successful learners, confident and creative individuals, and active and informed citizens' able to 'manage their emotional, mental, spiritual and physical wellbeing' (MCEETYA, 2008 pp. 8-9).

In 2012, the Gillard Government set a target for Australian students to rank within the top five OECD countries for educational performance by 2025 (Gillard, 2012). Subsequent governments have maintained this agenda and Savage and O'Connor (2018) argue that harnessing education to economic and social objectives is a trend among OECD countries. This is explicit in the OECD's (2018) *Learning Framework 2030* and in the goals that underpin the Australian Curriculum (Gonski et al., 2018). The most basic of these goals is attaining literacy and numeracy *essentials* (ACARA, 2010); these are prioritised across all key learning areas in the Australian Curriculum and are assessed, at a national level, through the National Assessment Plan Literacy and Numeracy (NAPLAN) testing in Years 3, 5, 7 and 9 (ACARA, 2019).

While NAPLAN results are meant to be a 'snapshot' of a student's achievement (ACARA/ NAP, 2017), there have been several unintended consequences, including intense test preparation in schools and an overemphasis on the test as an accountability measure (Cumming et al., 2018; Parliament of Australia, 2014).

Current research indicates that these consequences have led many parents and teachers to believe that, in terms of student wellbeing, the pressure surrounding NAPLAN outweighs any benefits (Matters, 2018; Rogers, Barblett & Robinson, 2018). Many stakeholders express concerns that the focus on competitive and standardised testing demonstrates a narrow conception of education (Cefai & Cavioni, 2015; Robinson, 2018; Velegrinis, 2017); denies the importance of 'soft skills' such as 'moral character, kindness, dependability or determination' (Watson, 2017, p. 15); and marginalises many students (Cumming, et al., 2018). Over 90% of eligible Australian students sat the 2017 NAPLAN tests (ACARA, 2017), although Queensland teachers and parents state that schools often discourage SEN students from sitting (Deloitte, 2017, p. 69). This illustrates the dilemmas around inclusion, when education is driven by a 'raising standards' agenda (Riddell et al., 2016). Booth, Ainscow and Dyson (1997) argue that market-driven and competitive education systems, when translated to the classroom, have the potential to make SEN students something of an 'organisational problem' (p. 337).

In its uniformity and wording, the Australian Curriculum could be a force for equity and inclusion (Foreman, 2015; Henderson & Jarvis, 2016). However, ensuring a quality education for all creates a 'tension between differentiation for individual student needs by schools and demands for uniformity by education authorities' (Hyde, Carpenter & Conway, 2014, p. 389). The 2015 Review of the Australian Curriculum identified educator concerns that the 'sheer size' of the Australian Curriculum impacts the capacity of schools to 'offer a tailored curriculum' for diverse student needs (DET, 2015b, p. 5). Indeed, the Review characterised the Australian Curriculum as 'manifestly deficient in its inclusiveness and accommodation of the learning needs of students with disability' (DET, 2015b, p. 8).

Under the Australian Professional Standards for Teachers (APST) (AITSL, 2017), teachers are obliged to differentiate the curriculum and learning experiences for individual students in safe and supportive classrooms. Standard 1.6 specifies an understanding of legislation and teaching strategies relevant to students with disabilities (AITSL, 2017). Although the Australian Curriculum 2.0 advises educators on what it means to provide educational opportunities to students with disabilities 'on the same basis' as their peers (ACARA, 2019a), a recent report found that uniformity of best practice might be compromised because the Australian Curriculum provides only ‘minimal implementation advice’ (ACARA, 2019b, p.9). This is supported by statistics that indicate only 41% of Queensland teachers expressed confidence in their abilities to appropriately differentiate the curriculum for SEN students (Deloitte, 2017, p. 74).

### 2.4.4. The state policy context

Apart from students with high level needs or where specified in their IEP, most students in Queensland schools – including those requiring additional learning support and most SEN students– access their year level curriculum, and are assessed and reported against, the achievement standard for their cohort (Department of Education, 2019c). Identifying the level of support required for a student (and the degree to which the student is entitled to additional support) is an inconsistent process across Australian schools due to differing funding models and definitions of disability (Anderson & Boyle, 2015; Forlin et al, 2013). Although a work in progress, the NCCD aims to improve consistency in definitions of, and funding for, disability in schools in line with the recommendations of the 2011 Gonski Review of Funding for Schooling (DET, 2018).

To receive an IEP, students in Queensland State schools must receive a specialist diagnosis or assessment of either ASD, intellectual disability, hearing, physical, speech-language and vision impairments (Department of Education, 2019a). As indicated in Chapter 1, Dyslexia and ADHD are defined as ‘learning difficulties’ in Queensland – these students do not require a formal diagnosis, are not eligible to receive an IEP in state schools and learning support is at the discretion and capacity of the school or region (Department of Education, 2018e). Students might receive additional support depending on the size and location of the school, with in-class teacher-aide support being the most common provision (Department of Education, 2018e).

Obtaining additional learning support and an IEP in Queensland schools is a process involving ‘collaboration and consultation with parents, the student (where appropriate), school curriculum leaders, classroom and support teachers and other relevant specialists’ (Department of Education, 2019a, pp. 4-5). Research indicates that these procedures also result in an inconsistent approach to the IEP process (Deloitte, 2017; Forlin et al., 2013) that is influenced by the school's SES and location (Children and Young People with Disability Australia [CYDA], 2016; Halsey, 2018); and that places parents and schools in an adversarial relationship (Boshoff, Gibbs & Phillips, Wiles & Porter, 2018; The Commission, 2017). These issues, that function as barriers to collaboration and inclusion, are not confined to Australia (MacLeod, Causton, Radel & Radel, 2017; Tétreault, et al., 2014).

In 1996, Australian educators raised an extensive list of concerns with the Disability Discrimination Commissioner. These identified a gap between the rhetoric of inclusion policy and the reality faced by educators, students and their families in providing and accessing adequate resources for inclusion practices (AHRC, 1996). The literature suggests that, more than twenty years later, in Australia, as in other countries, the situation is finally changing at a policy level. However, disparate assumptions and understandings about disability and inclusion persist (Deloitte, 2017; The Commission, 2017). Educators and parents have identified a need for serious discussion on how best to assess, support and fund the needs of SEN students in mainstream schools (Australian Association of Special Education*,* 2015; CYDA, 2017).

This is especially relevant to the identification of mental health disorders, and provision for these as disabilities in schools. The Department of Education, Queensland supports student mental health through procedures outlined in the *Supporting Student Health and Wellbeing Policy Statement* (2019), and students at risk might be referred to the school Guidance Officer or to external mental health services. However, the department does not recognise students with mental health challenges as warranting additional classroom support.

### 2.4.5. Wellbeing and learning – the national policy context

The Australian Government's focus on student wellbeing is set in the context of international initiatives such as the WHO's (2013) *Mental Health Action Plan 2013–2020*, focusing on policy environments that do not just address mental illness, but promote mental health. The *Australian Student Wellbeing Framework* (Education Council, 2018), which was endorsed by state and territory ministers, promotes whole school wellbeing through five elements: visible leadership, inclusive learning environments, authentic student participation, effective family and community partnerships and an emphasis on positive behaviours and appropriate early intervention (Education Council, 2018, pp. 3-4). Resources for parents, educators and students that support and expand the framework are organised under the online Student Wellbeing Hub (Education Council, 2018) and these include links to key online mental health programs.

### 2.4.6. Wellbeing and learning – the state policy context

Within the overarching structure of the *Australian Student Wellbeing Framework* (2018) sit state and territory positions on school-related student wellbeing which, in Queensland, is outlined in the *Student Learning and Wellbeing Framework* (Department of Education, 2018c). This is supported by the *Inclusive Education Policy* (2018), positive approaches to student behaviour such as Positive Behaviour for Learning, and *The Parent Community Engagement Framework* (Department of Education, 2013).

Both federal and state frameworks clarify the link between student wellbeing, education settings and inclusion (Department of Education, 2018c; Education Council, 2018) but do not represent a coordinated approach to student wellbeing. Orygen, the National Centre of Excellence in Youth Mental Health (2016) commented on the 'lack of clarity in the roles, responsibilities and accountabilities between and across governments' (p. 3). This statement illustrates the difficulties, encountered in this literature review, in clarifying how state and federal policy intersect: at the time of writing, neither the Commonwealth nor state government websites formally acknowledged the other's strategy or explained how they correspond. The siloed nature of state, territory and federal policy appears to affect the ability of educators – and parents – to find a single source of information or ‘truth’ about the current policy context. Combined with the lack of coordinated and multi-disciplinary approaches to mental health in schools, the intentions of both federal and state wellbeing initiatives might remain at the strategic stage, rather than effect real change for young people.

## 2.5. The bio-ecological system – the adolescent at the centre

### 2.5.1. The taxonomy of neurodiversity

The assessment process for students who require adjustments to the learning environment and additional support in Queensland schools, inevitably involves a medical classification and labelling. Research indicates that the issue of labelling is poorly understood and generally viewed in negative terms (McMahon, 2012): some educators argue that a label, once assigned, is immutable and serves to further marginalise and stigmatise students (Gillman et al., 2000; Jaarsma & Whelin, 2012; Ohan et al., 2011) and lower expectations for their schooling outcomes (Shifrer, 2013). Others argue, pragmatically, that the benefits labels provide, such as access to learning support, outweigh the detrimental effects (Guerra, Tiwari, Das, Cavazos Vela & Sharma, 2017). Riddick (2000) suggests that the impact of a label depends on who is applying it and in what context. Neurodiversity advocates confirm this perspective, arguing that science and neurology are not responsible for the stigma that results from how language is used (Armstrong, 2014; Ginsburg & Rapp, 2013). One of the most compelling reasons for a diagnostic label is that it gives a name to difficulties adolescents might have been experiencing (Chambers, Murray, Boden & Kelly, 2019); and, as Gutshall (2013) suggests, categories do not matter to educators with inclusive attitudes and positive mindsets.

Another issue with labels is the overlapping nature of Neurodevelopmental Disorders. There is sufficient research evidence to demonstrate the co-occurrence of ASD, ADHD and SLDs, and to suggest a common genetic heritage between ASD and ADHD (Antshel & Russo, 2019), Dyslexia and ADHD (Mascheretti, et al., 2017), and ASD and Dyslexia (Eicher & Gruen, 2015). As this body of research suggests, it is difficult to understand student needs based on labels where the boundaries are constantly shifting. The following characteristics of neurodiverse students focus on the challenges for these students in school environments rather than their strengths.

### 2.5.2. Characteristics of ASD

According to the DSM-5, individuals with ASD have a range, or ‘spectrum’, of social, behavioural and communication characteristics (autistic traits) that are present from early childhood and cause ‘significant impairment in social, occupational, or other important areas of current functioning’ (APA, 2013). Many social and learning contexts are challenging because of repetitive behaviours, restricted interests, difficulties with verbal and non-verbal communication and executive dysfunction (Aspect, 2018). These traits can ‘hinder daily functioning … and severely impede … educational and social attainments’ (WHO, 2013, p.7). The challenge of living with autistic traits can provoke extreme distress in children and adolescents with ASD: reactions to sensory stimuli or difficulties in understanding social communication; challenges to inflexible thinking patterns; or strong preferences for routine make generalised anxiety and social anxiety disorders an inherent aspect of ASD (APA, 2013).

In Australia, while most students with ASD are educated in mainstream classrooms, there is a strong perception, among students, of unmet needs (ABS, 2015a); and teachers have expressed concerns that their students with ASD underachieve relative to their ability (recorded IQ) (Ashburner, Ziviani & Rodger, 2010). Even for high functioning and academically able students with ASD, mainstream classrooms can be stressful sensory and social environments (Able, Sreckovic, Schultz, Garwood & Sherman, 2015; Goodall, 2018; Huw & Jones, 2008). The response to this stress – meltdowns and non-compliance – can be challenging for peers and teachers (Moyse & Porter, 2015) and distressing for the student with ASD; students have described their school experience in terms of ‘apprehension, dread and despair’ (Goodall, 2018, p. 6).

### 2.5.3. Characteristics of ADHD

While ADHD is the most common Neurodevelopmental Disorder in Australia (Goodsell et al., 2017).), research suggests the true rates of ADHD are unknown because of limited access to paediatricians (Efron et al., 2019). ADHD must be diagnosed according to the DSM-5 criteria by a paediatrician or psychiatrist (APA, 2013) and the fact that Queensland's Department of Education (2018c) does not require this formal diagnosis highlights the ambiguous status of ADHD in Queensland schools.

Students with ADHD often appear distracted, dislike tasks requiring sustained attention and describe feeling 'frustrated, angry, drained and/or imprisoned' by the long periods of inactivity during lessons (Gwernan-Jones et al., 2016, p. 91). As their executive functioning skills are characteristically poor, compromising organisation and time management, these students struggle to complete activities and homework (APA, 2013). Students with ADHD have described their difficulties with study skills, such as poorly organised notes and materials and procrastinating over assignments (Wiener & Daniels, 2016). They also typically lack the social skills of turn-taking and effective listening, which are important for peer acceptance. They might interrupt conversations, talk over others and use equipment without permission (APA, 2013); and these characteristics make social interaction difficult (Wiener & Daniels, 2016).

Other behavioural and mental health problems frequently co-occur with ADHD. Across education authorities, students with ADHD are more likely to be expelled or suspended (Ford et al., 2018; Parents for ADHD Advocacy Australia, 2019). Academic underachievement is a predictable consequence of these learning and social challenges, and by Year 9 Australian students with ADHD are up to five years behind their peers in academic achievement (Lawrence et al., 2016).

### 2.5.4. Characteristics of SLDs

Students with SLDs have 'unexpected and persistent' learning difficulties in the domains of reading (Dyslexia), writing (Dysgraphia) and mathematics (Dyscalculia) (APA, 2013). These are 'unexpected' because students' abilities are inconsistent with their cognitive assessment scores, and they are 'persistent' because standard classroom interventions have little impact (Le Messurier, 2017; Skues & Cunningham, 2011). Dyslexia accounts for around 80% of SLDs and between 10-20% of the population is on the continuum of mild to severe dyslexia (ADA, 2019).

There is a great deal of uncertainty and imprecision in naming, defining and categorising SLDs (Knight, 2018; Osterholm et al., 2007) and, because of this, children often do not receive an early diagnosis or appropriate support (Butterworth & Kovas, 2013). As assessment for SLDs is not required or available in Queensland schools (see Department of Education, 2018c), families must access private educational psychologists or diagnostic services (Delaney, 2017; Skues & Cunningham, 2011).

Students with Dyslexia also have poor working memory and executive functioning, negatively affecting time management and organisation (Le Messurier, 2017; Watson & Bond, 2007). These challenges impact academic motivation and engagement, which teachers and parents often misinterpret as disinterest or laziness (Chodkiewicz & Boyle, 2016; Gilmore & Boulton-Lewis, 2009; Livingston, Siegal & Ribary 2018). Persistent academic failure and a sense of inadequacy contributes to stress (Panicker & Chelliah, 2016) and anxiety (Francis, Caruana, Hudson & McArthur, 2019); and students have described not being able to cope with school and feeling ‘angry all the time’ (Leitão et al., 2017, p. 327). Their anxiety is connected to learning environments in which they do not succeed or feel supported, but in other respects, they do not experience anxiety to a greater extent than their developmentally typical peers (Bonifacci, Storti, Tobia, & Suardi, 2016; Novita, 2016).

### 2.5.5. Characteristics of NVLD

NVLD is not categorised in the DSM-5 and as less is known about NVLD, it is often misdiagnosed or overlooked. Individuals typically have well developed verbal skills but struggle with non-verbal judgement and perception, causing difficulties in social situations (Little, 2002). Poor motor skills and coordination affect their ability to interact with their peers; limited mathematical skills and poor organisational and visual-spatial abilities affect academic achievement and these students are often stigmatised as lazy (Fisher & Margolis, 2017). Unsurprisingly, they often experience social anxiety or are anxious about school (Mammarella et al., 2016).

## 2.6. **Student wellbeing and the school microsystem**

Mental health issues often first appear in adolescence and, while common, are disruptive to healthy adolescent development (Guy et al., 2016; Lawrence et al., 2016; Rickwood et al., 2019). As so much of adolescents' time is spent in school or school-related activities, schools are crucial settings for their social-emotional development and wellbeing (Jones, West & Suveg, 2019; Mazzer & Rickwood, 2015; Wallace et al., 2011). Accordingly, there is a long history of research into schools as settings for selective mental health interventions (Humphrey & Wigelsworth, 2016; Kutcher, Bagnall & Wei, 2015; Vostanis, Humphrey, Fitzgerald, Deighton & Wolpert, 2013); and the relative success of these programs (Maag & Katsiyannis, 2010; Wallace et al., 2011). Recent Australian research has focused on the benefits and challenges of whole-school positive psychology programs (Halliday, Kern, Garrett & Turnbull, 2019; Kern, Adler, Waters & White, 2015; Slemp et al., 2017); although it has been proposed that these interventions are most effective as part of a whole-school philosophy towards wellbeing (Schonert-Reichl & Lawlor, 2010; Seligman, 2011), Chodkeiwicz and Boyle (2016) suggest that wellbeing programs are more often 'add-ons' to the school timetable and that numerous factors, including an overcrowded curriculum and teacher attitudes and training, impact their efficacy and uptake.

Rather than trusting student wellbeing to additional interventions, an ecological perspective of school-related wellbeing focusses on the interaction between the student and the school social and learning environments. A large body of Australian and international research emphasises the fundamental importance of positive, safe, and supportive school environments as protective factors in adolescent mental health and wellbeing (Cefai & Cavioni, 2015; Riekie, Aldridge & Afari, 2017; Toumbourou, Hall, Varcoe & Leung, 2014). An equal research effort has been devoted to understanding the dimensions of such environments (Thapa, Cohen, Guffey & Higgins-D'Alessandro, 2013; Ramelow, Currie & Felder-Puig, 2015). Aldridge and McChesney (2018) examined the literature on school climate and adolescent wellbeing from an ecological systems perspective and demonstrated a connection between student wellbeing and positive relationships with teachers and peers; feeling connected to school; and feeling safe at school. They found that overly competitive cultures that place excessive academic pressure on students are associated with mental health issues and risk behaviours. Students' perception of academic pressure relates to their perceptions of academic demand relative to perceptions of their ability (Aldridge & McChesney, 2018). However, the authors suggest that the connection between the academic environment and psychosocial wellbeing is underexplored; future research is required to ''fill out' the picture' (p. 137).

Neurodiverse students' perceptions of ability and academic demands, and what they perceive as feeling supported and included in the classroom, frequently differ from their peers; however, their voices are largely missing from the literature on positive, safe, and supportive school environments. (Livingston et al., 2018; Sproston et al., 2017; Weiner & Daniels, 2016). It is important, therefore, to understand the relationship between school settings and student mental health for students who experience learning and/or social difficulties.

This section of the literature review explores the research relevant to the school-related wellbeing of typically developing adolescents, adolescents with SEN, adolescents with mental health disorders and neurodiverse adolescents. Themes common to this literature base were identified as: *belonging and connectedness*, *peer relationships* and *positive relationships with teachers within supportive learning environments* and are illustrated in Table 1 (included as Appendix A). These themes provide the organising structure for the following outline of the neurodiverse student's microsystem.

### 2.6.1. Background – the schooling context for early adolescence

As the participants' children were, on average, between Years 7 and 9 at the time of interview, this review considered school-related wellbeing against the contexts of transitions between primary and high school, and within a middle schooling approach. The successful engagement of adolescents in the early years of high school is crucial to success in the senior secondary years and beyond (Benner, Boyle & Bakhtiari, 2017; Crump & Slee, 2015; Zeedyk et al., 2003). However, research into the concept of Stage-Environment fit (Eccles et al., 1993; Eccles & Roeser, 2010,

2011) suggests that there is a poor fit between the typical high school environment and adolescents' developmental needs that significantly contributes to low wellbeing.

Typically, the transition to high school sees a decline in, or interruption to, academic functioning (Hopwood, Hay & Dyment, 2017; Vaz et al., 2014), and most students experience some anxiety and social isolation (Riglin, Frederickson, Shelton & Rice, 2013; Waters, Lester & Cross, 2014), at least temporarily, due to increased academic pressures and new social contexts (Gillison, Standage, & Skevington, 2008; MCRI, 2018a). Transitioning students have expressed concerns about navigating different settings and peer relationships (Topping, 2011), they perceive the student-teacher relationship as more formal and less personal (Tobell & O'Donnell, 2013), and they find the workload more challenging in high school (Maher, 2010; MCRI, 2018a).

Benner and colleagues (2017) suggest that it is the disruption to adolescents' social relationships when transitioning from primary to high school environments that primarily compromises their academic engagement and SEWB. This is especially relevant to SEN students for whom continuity of learning support and relationships is highly important (Crump & Slee, 2015; Makin, Hill & Pellicano, 2017). Transitioning from the familiar and (often) supportive environment of primary to high school can be challenging and distressing (McMaugh, 2011) and requires careful planning and coordination (Bailey & Baines, 2012; Forlin, 2013). However, research indicates that, across Australia, inconsistent transition strategies and practices negatively impact the experiences of SEN students (O'Neill, Strnadová & Cumming, 2016; Strnadová & Cumming, 2014; Tso & Strnadová, 2017).

Maras and Aveling (2006) propose that the nature of the students' specific disability determines the type of stressor influencing their experience. For example, students with ASD are often challenged by the frequent changes to routine at high school (Hannah & Topping, 2012) and by navigating their new school's physical and social environments (Dann, 2011; Fortuna, 2014); whereas students with SLDs experience lowered academic self-esteem (Forgan & Vaughn, 2000) and develop maladaptive academic coping skills such as learned helplessness (Firth, Frydenberg, Steeg & Bond, 2013) .

### 2.6.2. Student connectedness and belonging

Adolescence is marked by a growing need for autonomy and independence from parents (Park & Holloway, 2013; Steinberg, 2014); adolescents begin to rely more on their peer group for social support and are highly sensitive to peer influences (Benner 2018). Peer interpersonal relationships become extremely important for adolescents' quality of life and enable students to manage transition changes effectively (Gillison et al., 2008; Waters, Lester, Wenden & Cross, 2012; Waters et al., 2014). A perception of connectedness and of physical and emotional safety, which includes freedom from peer victimisation and harassment, are important aspects of positive school environments (Aldridge & McChesney, 2018; E.S.A, 2018; Riekie, et al., 2017; Thapa et al., 2013).

Bowles and Scull (2019) suggest that belongingness and connectedness essentially refer to a 'goodness-of-fit' between student and school community that 'enhances wellbeing, adjustment and development' (p. 12). Studies demonstrate that a sense of belongingness and connectedness is associated with a feeling of safety at school (Joyce & Early, 2014), positive relationships with teachers (Wallace, Ye & Chhuon, 2012), positive academic outcomes (Allen & Bowles, 2012; Prince & Hadwin, 2013; Waters, Cross & Shaw, 2010), and a sense of community at school (Rowe & Stewart, 2011). Conversely, negative behaviours, low motivation and alienation occur when a student's need to belong and connect with the school community are not met (Osterman, 2000). Not belonging is associated with mental illness (Flook, Repetti & Ullman, 2005), low wellbeing (Redmond et al., 2016; Robinson & Truscott, 2014), and decreased academic motivation and performance (Flook et al., 2005). Although belongingness and connectedness are particularly important for SEN students (Pham & Murray, 2016; Robinson & Truscott, 2014; Vaz et al., 2014), their general experience appears to be one of alienation from their school community (DSS, 2009; Deloitte, 2017; Hogan, McLellan & Bauman, 2000; Urbis, 2015; The Commission, 2017).

Peer acceptance is a separate, less affirming, construct to friendship but is nevertheless, a critical 'entry-level' aspect to student belonging that involves being liked by one's peers (Mikami, 2010). Peer acceptance is influenced by peer attitudes to disability (de Boer, Pijl, Post, & Minnaert, 2013) and de Boer & Pijl (2016) suggest that type of disability appears to matter – they found that students with ADHD, followed by students with ASD, were least accepted as potential friends, and most rejected by typically developing secondary students. McDougall, DeWit, King, Miller and Killip (2004) found that adolescents generally accepted the idea of students with disabilities at school. However, in terms of belonging and connectedness, there is a significant difference between typically developing students 'accepting the presence of students with disability at school and valuing their membership as part of the school community' (Robinson & Truscott, 2014, p. 19).

### 2.6.3. Peer relationships

Positive friendships play an important role in general adolescent wellbeing (ESA, 2018) and in the wellbeing of neurodiverse adolescents (Claassens & Lessing, 2015; Leitão et al., 2017; Livingston, et al., 2018; Mikami, 2010; Sproston et al., 2017). However, compared with their typically developing peers, the social relationships of SEN students are fewer and of poorer quality (Humphrey et al., 2013; McMillan & Jarvis, 2013) and they commonly report feelings of loneliness (Benner et al., 2017; Maxey & Beckert, 2016; Robinson & Truscott, 2014).

Guerra and Bradshaw (2008) suggest that social and emotional competencies, such as self-awareness, self-control, self-efficacy and self-esteem, are essential aspects of healthy psychological adjustment and promote positive friendships. Yet neurodiverse adolescents often lack these attributes: young people with ASD typically lack self-awareness and emotional regulation (Hill, Berthoz & Frith, 2004; Huw & Jones, 2008). They might have a limited understanding of the nature of friendship; their friendships are less likely to be reciprocated by the nominated friend; and are highly dependent on parent intervention (Bauminger & Shulman, 2003; Petrina, Carter & Stephenson, 2014). Vine Foggo and Webster (2017) demonstrated a discrepancy between the apparent and actual friendship needs of adolescent girls with ASD, who wanted friends but had difficulty understanding expectations around friendships or the social norms of groups. These issues around social skills have been associated with high levels of loneliness (Deckers, Roelofs, Muris & Rinck, 2014) and social anxiety (Spain, Sin, Linder, McMahond & Happé, 2018).

Compared with their neurotypical peers, adolescents with ADHD generally have fewer friends, and their friendships are less stable and are more problematic (Bagwell, Molina, Pelham & Hoza, 2001; Marshal, Molina & Pelham, 2003). This is related to their difficulties with self-control – conduct problems, emotional regulation and impulse-control are all issues (Kok, Groen, Fuermaier & Tucha, 2016; van Stralen, 2016). Adolescents with ADHD also tend to overestimate the quality and number of friendships (Mikami, 2010).

Social skill issues are not characteristics of learning difficulties, and adolescents with SLDs do report positive and supportive friendships (Leitão et al., 2017). However, students with SLDs typically have low self-efficacy and self-esteem (Claassens & Lessing, 2015; Novita, 2016). Shame related to persistent academic failure can cause them to withdraw from peers (Riddick, 2010) and that impacts their classroom participation.

Negative peer perceptions of neurodiverse students' behaviours and stigma associated with otherness and difference are central to the lived experience of young people with: ASD (Farrugia, 2009; Shtayermman, 2009; Russell & Norwich, 2012); ADHD (Gwernan-Jones et al., 2016; Wiener & Daniels, 2016); SLDs (Leitão et al., 2017; Riddick, 2000, 2010); and mental health disorders (Hinshaw, 2005; Kaushik et al., 2016). De Luca (2019) reviewed the literature on adolescent mental illness and stigma and found that, while adolescents had significant gaps in their mental health literacy, they held generally negative views on, and emotional responses to, mental illness. Students with mental health disorders were perceived as less desirable group members and 'typical' adolescents preferred social and physical distance from peers with behavioural problems such as ADHD. This suggests that neurodiverse students with anxiety are at an increased risk of social isolation as a result of stereotype-related discrimination and prejudice, relating to both their social difficulties and mental illness.

Bullying and peer victimisation is a serious concern in early adolescence, and there is a reciprocal and self-perpetuating relationship between adolescents' social exclusion, bullying, social isolation and psychological distress (Juvonen, Graham & Schuster, 2003; Menesini & Salmivalli, 2017). And there are serious academic consequences: the bidirectional relationship between academic outcomes and student wellbeing is well-established (Education Council, 2018; Jones et al., 2019; Suldo, Gormley, Du Paul & Anderson-Butcher, 2014) and is demonstrated in the NAPLAN results of students with mental health disorders, which can be nearly three years behind peer averages by Year 9 (Goodsell et al., 2017). Researchers at the Murdoch Children's Research Institute (MCRI) (2018b) found that students with low levels of wellbeing were more likely to be disengaged and fall behind their peers in learning outcomes: students who are bullied in primary school are nearly a year behind their peers in academic achievement by high school (p. 4). The authors suggest that if schools take care of student wellbeing, student engagement will follow. As Skreckovic, Brunsting and Able (2014) state, 'students will not perform well in school if they do not feel safe in school' (p. 1164).

Espelage and Holt (2001) suggest that bullying behaviours during late primary and early high school are less about the individual relationship between bully and victim, but about the general need to fit in within a peer group. Bystanders become part of the problem as they are caught in the same social need to fit in (Menesini & Salmivalli, 2017; Swearer, Espelage, Vaillancourt & Hymel, 2010) and rely on group norms and stereotypes to decide who should be included or excluded (Horn, 2003). As peer acceptance of students with disabilities is influenced by stereotype beliefs (McDougall et al., 2004), this illustrates the processes by which neurodiverse students are stigmatised and excluded by their peers (Livingston, et al., 2018).

SEN students report being victimised more often than typically developing peers (Prince & Hadwin, 2013; Rigby & Johnson**,** 2016). Surveys and meta-analyses of the literature on neurodiverse children and adolescents indicate that peer victimisation is a common experience for students with: SLDs (Livingston et al., 2018); ASD (Kloosterman, Kelley, Craig, Parker & Javier, 2013; Sreckovic, Brunsting & Able, 2014); and ADHD (Mikami, 2010). Prevalence of bullying varies by disability type (Rose, Swearer & Espelage, 2012) and this also determines whether students experience victimisation more frequently in Special Education settings or when included in mainstream classrooms.

Neurodiverse young people with 'invisible disabilities' experience more victimisation in mainstream settings (McDougall & Vaillancourt, 2015; Rose et al., 2012; Rose, Simpson & Green, 2015) and these adolescents report generally negative experiences of social, emotional and physical isolation from peers (Goodall, 2018; Salmon, 2013). Students with co-occurring conditions experience higher levels of victimisation than other SEN students (McLaughlin, Byers & Vaughn, 2010).

Friends generally shield against victimisation (Pellegrini & Long, 2002; Zeedyk et al., 2003), so an inability to form strong friendship groups puts neurodiverse students at risk of the negative psychosocial effects of peer rejection (Humphrey, Storch, & Gefken, 2007; McMillan & Jarvis, 2013; Petrina et al., 2014; Rosbrook & Whittingham, 2010; Rose et al., 2015).

Rieke et al (2017) demonstrate that positive and inclusive school climates that affirm diversity help to constructively shape students' sense of moral identity. Such school environments include whole school norms and values that promote a sense of safety, belongingness and connectedness through caring and supportive relationships between students, and also with key adults in the school environment (Aldridge & McChesney, 2018; McLaughlin et al., 2010).

### 2.6.4. Supportive and inclusive learning environments

Supportive relationships with key adults at school are important for academic engagement and wellbeing in typically developing students (Noble et al., 2008; ESA, 2018; Moore et al., 2018) and even more so for neurodiverse students (Maxey & Beckert, 2016; Pham & Murray, 2016; Robinson & Truscott, 2104; Vlachou & Papananou, 2015). Paterson, Graham and Stevens (2014) evaluated effective equity and inclusion programs across seven Australian secondary schools and found that not only were these schools strongly collaborative and well-resourced, but shared strong relationships between students and teachers, and focused on individual student needs. The same qualities have been found in other inclusive schools (Abawi, 2015; Centre for Education Statistics and Evaluation [CESE], 2018). However, the learning, social-emotional and behavioural difficulties of neurodiverse students present additional professional challenges that can impact the student-teacher relationship (Able et al., 2015; Guerra et al., 2017; Knight, 2018; Macfarlane & Woolfson, 2013; Sproston et al., 2017). There are widespread concerns over the capacity of teachers to effectively accommodate the needs of SEN students in mainstream classrooms (ACARA, 2012; CYDA, 2017; DSS, 2009; Deloitte, 2017; The Commission, 2017).

Moreover, inclusion practices appear to be especially inconsistent in secondary schools (Forlin et al., 2013).

More than 25 years ago Eccles and colleagues (1993) commented on how difficult it was for secondary teachers to feel ‘efficacious about their ability to monitor and help all of [their] students’, given subject organisation and timetable demands (p. 94). These structural issues remain and affect teachers’ beliefs in their capacity to overcome challenging teaching situations, adopt new teaching practices, or implement the type of flexible teaching arrangements that facilitate inclusion and differentiation (Round, Subban & Sharma, 2016; Woodcock & Reupert, 2016).

Thompson and Timmons (2017) depicted the ‘hope-filled’ and positive ethos in a Canadian school, which described its whole-school inclusion practices as the ‘full meal deal’ (p. 74). Nevertheless, the school’s education and support professionals still expressed concerns about how to ‘do’ authentic inclusion in secondary schools for SEN students. In particular, they worried about how to get the right balance between developing necessary functional and academic skills and encouraging social skills without segregation or over-reliance on paraprofessionals. While they generally express positive attitudes towards inclusion, teachers in Australia and overseas have similar concerns. They are worried about their theoretical and practical knowledge of neurodiverse students’ needs and attribute this to inadequate pre-service and/or in-service training (Able et al., 2015; Boyle, Topping & Jindal-Snape, 2013; Knight, 2018; Rodden, Prendeville, Burke & Kinsella, 2019). Even when in-service training is available, teachers state that conflicting schedules often prevent them from attending (Guerra et al., 2017). Professional and peer collaboration is important to teachers’ sense of efficacy towards including SEN students (Boyle, Topping, Jindal-Snape & Norwich, 2012; Maxey & Beckert, 2016). However, teachers are concerned about the difficulties attached to planning with other staff, as well as the administrative load of inclusion and the time constraints associated with each (Subban & Sharma, 2016). Teachers frequently cite inadequate administrative support and resources as barriers to inclusive practice (Boyle et al., 2013).

Maciver and colleagues (2018) argue that inclusion practices are largely tailored to the needs of younger learners, not adolescents, and they believe that there is a lack of guidance around effective inclusion in the secondary context. The authors examined how experienced and effective Scottish teachers included adolescents with neurodevelopmental, physical and emotional disabilities (aged 12-18) in their mainstream classes; and their findings substantiate other studies that articulate practices valued by neurodiverse students.

Among numerous effective strategies, the authors found that inclusive teachers understand the importance of ensuring all learners feel valued through recognition of individual strengths (Maciver et al., 2018). This is viewed as an act of caring by secondary students in general (Garza, Lee & Ryser, 2009) and especially by neurodiverse students who want to be ‘understood, supported and included’ (Goodall, 2018, p. 1), or who perceive that their strengths often go unrecognised in mainstream environments (Livingston, et al., 2018). Teacher attitudes to inclusion are strongly influenced by their understanding of a student’s diagnosis or needs (Avramidis, Bayliss, & Burden, 2000, 2002; Gibbs & Elliott, 2015; Guerra et al., 2017; Woodcock & Reupert, 2016). For example, teachers perceive that their ability to effectively include students with ASD is impacted by their confusion over the many possible implications of the student’s diagnosis (Able et al., 2015).

The extent of teachers’ knowledge of neurodiverse students’ needs is a recurrent theme in the literature and qualitative research indicates that these students value teachers who set tasks that make success accessible (McMillan & Jarvis, 2013); who do not underestimate their abilities just because they might learn in a different way (Vlachou & Papananou, 2015); and who demonstrate an understanding of their diagnosis and needs (Roberts & Simpson, 2016). Claassens and Lessing (2015) asked young adult learners with Dyslexia about what would have made a difference to them in high school. In general, the participants felt that teachers, especially in the mainstream setting, do not understand the condition or how to deal with the student with Dyslexia. They emphasised the need for teachers to show patience and to avoid insensitive remarks that drew attention to their difficulties. Other studies reinforce these findings – students repeatedly express the need for tolerance and support and for recognition of their diagnosis (Leitão et al., 2017; Mattson & Roll-Pettersson, 2007).

Maciver and colleagues (2018) also found that inclusive teachers build positive relationships. In part, this involves firm and consistent expectations for behaviour:

this is important for students with ADHD, who often feel unfairly punished for behaviours that are beyond their control (Gwernan-Jones et al., 2016; Wiener & Daniels, 2016). This also involves teachers considering the possible underlying causes of negative behaviours (Maciver et al., 2018): commonly, teachers feel challenged by the behaviours of students with ADHD and ASD and do not feel confident or positive about including them in the mainstream classroom (Ashburner et al., 2010; Guerra et al., 2017). Gwernan-Jones and colleagues (2016) made specific recommendations that teachers be provided with training to help them understand the 'triggers' for poor behaviour in students with ADHD and the 'neurocognitive basis for ADHD behaviours rather than attributing them to deliberately provocative student behaviour' (p. 96).

## 2.7. The parent-child microsystem

Of all the relationships between children and others in their immediate environments, Bronfenbrenner (1986, 2001b) theorised that the parent-child relationship is the most proximal, therefore the most critical to positive development. There is a comprehensive and well-established research base that supports this proposition, and that explores the significance and bi-directionality of parent-child interactions (Steinberg, 2001; Steinberg & Morris, 2001). There is also extensive research documenting the ecologies of these interactions (Eriksson, Ghazinour & Hammarstrom, 2018; Waters, Cross & Runions, 2009). A detailed review of either literature base is beyond the scope of the current study, however this section provides a brief overview of parent cognitions, as these strongly influence parenting behaviours such as involvement and engagement in education (Benner & Boyle, 2016; Green, Walker, Hoover-Dempsey & Sandler, 2007; Hornby & Lafaele, 2011).

### 2.7.1. Parent cognitions

Parent cognitions represent parents' knowledge about child development and childrearing strategies (Goodnow, 2002), as well as their 'beliefs, attitudes, perceptions, attributions, and expectations about children [and] families and … what it means to be a parent' (Okagaki & Bingham, 2005, pp. 3, 5). Parent cognitions are dependent on the family's socio-cultural context (Goodnow, Goodnow & Collins, 1990). For example, parents' hopes and expectations for their child's education are important for academic achievement (Benner, Boyle & Sadler, 2016) but are influenced by parental material resources (Chesters, 2016); education levels (Bornstein, Cote, Haynes, Hahn & Park, 2010); cultural capital (Woodrow, Somerville, Naidoo & Power, 2016); social class (Irwin & Elley, 2013); and social aspirations (Roska & Potter, 2011). Parent cognitions also represent the dynamic relationship between the parent's and the child's individual characteristics and the ecologies in which parents live, work and raise their families. As Lerner, Rothbaum, Boulos and Castellino (2002) explain, 'children and parents are fused, both structurally and functionally, in a multilevel system involving biological through sociocultural and historical tiers of organization' (p. 317).

### 2.7.2. The influence of parent cognitions on parent behaviours

Child development is most strongly influenced by parent cognitions that directly affect parenting decisions and behaviours (Belsky, 1984), that is, beliefs that parents act on as opposed to those that they simply espouse (Okagaki & Bingham, 2005). For example, parents' beliefs about whether intelligence is fixed or malleable affect the extent to which they encourage their child's efforts at school. Parents who have a 'growth' mindset rather than a 'fixed' mindset towards intelligence believe that their child has the capacity to improve performance (Dweck, 2012). Parents act on this belief through active engagement in their child's education (Hoover-Dempsey & Sandler, 1997). Rautiainen, Räty and Kasanen (2016) demonstrated a reciprocal relationship between the child's academic performance and parent beliefs. The authors demonstrated that the participants had fixed attitudes to their child's successful academic performance and attributed it to intelligence. However, they attributed poor performance to factors other than intelligence and were willing to help their child improve at school. Studies indicate that parents of underachieving neurodiverse children demonstrate similarly malleable beliefs about their child's academic and social abilities, and researchers attribute these beliefs to the parents' unique insights into their child's strengths (Kapp et al.2012; McIntyre & Hennessy, 2013).

Parental role construction (Hoover-Dempsey & Sandler, 1997), or parents' beliefs about the importance of education, and what they *should* do to help their child, matter (Hornby & Lafaele, 2011); so do parental beliefs about what they are *able* to do. What parents believe they can do affects what they *actually* do to support their child's education, and this matters most. Parent efficacy beliefs reflect parents' perceptions of, and confidence in, their capacity to effectively raise their child (Bandura, 1997; Coleman & Karraker, 2006; Jones & Prinz, 2005). Parenting efficacy has a mutual association with parent well-being (Johnston & Mash, 1998); determines positive parental aspirations (Kuhn & Carter, 2006); and influences parent involvement in school (Hoover-Dempsey et al., 2005).

Belsky (1984) proposed three key determinants of parenting behaviours – the first is parents' personal psychological resources, which include parenting cognitions (Bornstein, 2006); the second is the child's individual characteristics. There is a bilateral socialisation process by which parents convey their values and beliefs about education via their parenting behaviours, and also receive information on the degree to which their child accepts and internalises these views (Spera, 2005). Research demonstrates that parents of neurodiverse adolescents with social-emotional problems experience lower self-efficacy beliefs, either because their child's complex needs add to parental burden (Giallo, Wood, Jellet & Porter, 2013; Parsons, Lewis & Ellins, 2009; Weiss, Tint, Paquette-Smith, & Lunsky, 2016); or because the child's atypical or difficult behaviours confront their parents' expectations of how children should behave (Coleman & Karraker, 2006); or because parents perceive negative reactions to their child's behaviour or evaluations of their parental competence from others (Courcy & des Rivières, 2017; Gray, 2002; Kinnear, Link, Ballan & Fischbach, 2015). Eaton, Ohan, Stritzke and Corrigan (2016) demonstrated that, while mothers hold strong beliefs about what constitutes the 'perfect parent' and 'ideal child', the challenge of parenting a child with social-emotional and behavioural disorders, and their perception that they are being stigmatised for their parenting behaviours by others, causes these mothers to feel that they have failed to live up to these ideals.

The third determinant of parenting behaviours is contextual sources of stress and support (Belsky, 1984). For example, social networks can be contextual sources of stress or support and numerous studies have shown that frequent and positive interactions with other parents at school increase parents' beliefs in their ability to be involved in their child’s education (Cochran & Walker, 2005; Hoover-Dempsey et al., 2005; Sheldon, 2002; Woodrow et al., 2016). This further reinforces parents’ beliefs that they can interact positively with other parents (Curry & Holter, 2015; Curry, Jean-Marie & Adams, 2016).

### 2.7.3. Parenting style

Parent cognitions also influence parenting style: the degree to which parents demonstrate emotional warmth and responsiveness to their child’s needs and set behavioural and moral expectations for their child (Baumrind 1991). Baumrind’s original typology of authoritative, authoritarian and permissive parenting styles was extended by Maccoby and Martin (1983) to include neglectful parenting. Extensive research has demonstrated the effect of parenting style, or the ‘emotional climate’ at home (Darling & Steinberg, 1993) on child developmental outcomes, behaviours and emotional states. In particular, it is well established that an authoritative parenting style – firm, responsive and democratic – is most effective in terms of positive child outcomes (Steinberg, 1990; see also Darling & Steinberg, 1993; Steinberg, Lamborn, Darling, Mounts & Dornbusch, 1994; Steinberg, 2001).

Parenting behaviours associated with parenting styles include parental monitoring, which is a parent’s awareness of and interest in their child’s daily life – school experiences, friendships, activities and routines (Dishion & McMahon, 1998). Kerr, Stattin and Burk (2010) point out that, for young children, ‘vigilant parental monitoring’ is an essential aspect of effective and protective parenting (p. 39). However, if children are to develop a sense of wellbeing and self-efficacy, as well as autonomous and responsible behaviours, parents need to match their level of control and monitoring to their child’s developmental level (Segrin, Givertz, Swaitkowsky & Montgomery, 2015). While parental monitoring normally declines as adolescence progresses (Smetana & Rote, 2015), studies suggest a growing tendency among contemporary parents to be highly involved in the lives of their adolescent and young adult children, with negative consequences (Odenweller, Booth-Butterfield, & Weber, 2014; Schiffrin & Liss, 2017).

‘Intensive parenting’ (Hays, 1996), ‘parenting out of control’ (Nelson, 2010), or ‘overparenting’ (Segrin et al., 2015) are all terms for an intrusive style of parenting that shares the negative and controlling aspects of authoritarian parenting and the overly responsive aspects of permissive parenting. Segrin, Woszidlo, Givertz, Bauer and Taylor Murphy (2012) identify some of the key features of overparenting as 'risk aversion, a preoccupation with the child's happiness, and the drive to solve problems for the child, perhaps before they even develop' (p. 240). While 'overparenting' is usually well-intentioned, parenting behaviours are developmentally inappropriate and might extend beyond childhood and into early adulthood (Nelson, 2010; Padilla-Walker & Nelson, 2012; Segrin et al., 2015).

In popular discourse, 'helicopter', 'lawnmower' or 'snowplough' parenting describes the oversolicitous or 'hovering' behaviours of 'hyperinvolved' parents who micro-manage children's activities and emotional states, remove all obstacles between their child and achievement and who are willing to step in and prevent negative outcomes in daily social and academic experiences. Because autonomy-granting is such an important aspect of parenting adolescents (Filus, Schwarz, Mylonas, Sam & Boski, 2018), discussions on contemporary parenting portray these parents in a highly negative light. But Padilla-Walker, Son and Nelson (2019) argue that it is important to understand parent motivations for 'helicopter' parenting. The authors propose that being highly invested in their child's educational and social outcomes might be the parents' response to a perceived weakness, need or limitation in their child. In the case of neurodiverse children, there is substantial research demonstrating a gap between parent and professional assessment of the child's problems and needs and the parents' perception of that need being met at school (Armstrong, 2014; Boshoff , Gibbs, Phillips, Wiles & Porter, 2016; Cooc, 2018; Locke, Campbell & Kavanagh 2012; Ryan & Runswick-Cole, 2008).

The current study was not designed to evaluate the participants' parenting style or determine any kind of 'quality' rating for their parental competence. However, parents of neurodiverse children report feeling stigmatised by negative assessments of their parenting and that others see their children's difficult behaviours as a reflection of their parenting style and competency (Courcy & des Rivières, 2017; Eaton et al., 2016; Gray, 2002; Kinnear et al., 2015). The current study supports Padilla-Walker and colleague's (2019) suggestion that negative interpretations of 'overinvolved' parenting behaviours potentially over-simplify these parents' complex motivations for being highly involved in their neurodiverse child's schooling and education.

## 2.8. The parent-school mesosystem

There is an extensive research history on parent-school relationships. This literature, and government policies relating to the mesosystemic interactions between parents and schools, use a confusing array of terms to describe parents' active and direct participation in their child's schooling and school community; parents' interest in, and contribution to their child's broader, holistic education; the varying degrees of school efforts to include parents in schooling; and the varying degrees of interaction between families and schools (Goodall, 2018; Wilder, 2014). Several key principles were drawn from the review of this literature:

### 2.8.1. Parent involvement and engagement

*Parental involvement in schooling and engagement in education have generally positive effects but they differ and so does the relative impact*

As a general construct, parent participation in education is key to improved school and student outcomes, with positive effects on student well-being, resilience, motivation and achievement (Benner et al., 2016; Emerson, Fear, Fox & Sanders, 2012b; Epstein et al., 2019; Epstein & Sheldon, 2006; Henderson & Mapp, 2002; Jeynes, 2012; Hill & Taylor, 2004); and general benefits for staff capacity, school culture and the wider community (Bull, Brooking & Campbell, 2008; Department of Education and Children's Services, South Australia, 2011). Participation has been differentiated into 'school-based' and 'at-home' activities (Borgonovi & Montt, 2012; Epstein et al., 2019) and the terms 'parent involvement' and 'parent engagement' are often applied respectively; however they are used inconsistently and interchangeably in the literature (Stefanski, Valli & Jacobson, 2016). The current study adopts the view of authors such as Auerbach (2007) and Goodall and Montgomery (2014) that there is a qualitative difference between parent involvement in the life of the school and parent engagement in the 'academic socialisation' of their children, but that both occur on a continuum of interest and effort and are important contributors to effective parent-school relationships.

Parent involvement in schooling can be conceptualised as school-based and initiated activities that range from helping with homework (Hoover-Dempsey et al., 2001), to parent-teacher conferences (Hornby & Blackwell, 2018), to participation in the wider school community through supporting and volunteering activities such as the Parents and Citizens Association (Epstein & Salinas, 2004; Park & Holloway, 2013; Povey et al., 2016). From a school (and policy) perspective, promoting 'parent involvement' is what schools do to encourage parent interest and participation. From a parent perspective, their manner of involvement depends on a number of factors, including school climate, invitations from the school, and parent cognitions about education and their parenting role (O'Hehir & Savelsberg, 2014; Walker, Wilkins, Dallaire, Sandler & Hoover-Dempsey, 2005). Pushor (2007) suggests that the main benefit of parent involvement lies in its capacity to bring parents and teachers together to work towards a common goal; however, unless all these efforts are directly focused on learning, parent involvement is not as significantly linked to achievement as parent engagement in education (Goodall, J., 2013, 2018; Harris & Goodall, 2007). Positive parent cognitions and behaviours related to 'academic socialisation', or encouraging learning at home, have the greatest effect on student achievement, particularly for adolescents (Hattie, 2009; Hill & Tyson, 2009).

Parent engagement in education can also be conceptualised in two ways – from the parent perspective it is a sense of shared responsibility for their child's educational outcomes and the promotion and modelling of positive educational values and expectations at home (Desforges & Abouchar, 2003; Goodall, 2013). From a school perspective, schools that actively engage parents in their child's education admit the concept of shared responsibility for the child by including parents in decision-making processes (Weiss, Lopez & Rosenberg, 2010) and acknowledging parent knowledge and expertise (Pushor, 2017; Pushor & Ruitenberg, 2005). Schools that participated in Hornby & Blackwell's (2018) 'update' study on parent involvement indicated that concern for student wellbeing is the most significant driver for recent strategy changes – schools are increasingly willing to adopt an 'open-door' approach for parents out of a more active social awareness. In Australia, schools are increasingly taking on the role of ‘community hubs’ to connect school, families and community (Department of Education, South Australia, 2019). Not only do these efforts recognise that some families benefit from additional support (Goodall, J., 2018) but they help build community trust in education (Bentley, & Cazaly, 2015: Mapp, Johnson, Strickland & Meza, 2008). As several authors suggest, ultimately, the relationship between parents and schools should be an enabling one, that allows parents to positively relate to their child’s education in a manner that responds to parent and child needs, rather than a one-size fits-all model of ideal ‘parent involvement’ (Goodall & Montgomery, 2014; Posey-Maddox & Haley-Lock, 2016).

### 2.8.2. Parents feel outside the decision-making process

*On the whole, parents want to be involved in their child’s schooling but feel outside the decision-making process.*

Research indicates that most parents want to be involved in their child’s schooling (Hanafin & Lynch, 2002; Hoover-Dempsey et al., 2005; Jennings & Bosch, 2011; Peters, Seeds, Goldstein & Coleman, 2007) and while Australian parents appear to feel that their involvement efforts are appreciated, their concept of involvement appears to be limited to peripheral roles (Velegrinis, 2017). The policy rhetoric of building parent-school ‘partnerships’ does not always translate into school practice (Epstein & Sheldon, 2006; Hornby & Blackwell, 2018; Hornby & Lafaele, 2011) and schools do not necessarily clarify how they wish parents to be involved, or the ways parents can contribute to improving student learning outcomes (Edstar, 2007; Emerson et al., 2012b; Harris & Goodall, 2007; Mapp, 2004; Weiss & Stephen, 2009).

In their review of research relevant to Hoover-Dempsey and Sandler’s (1997) model of parent involvement, Hoover-Dempsey and colleagues (2005) proposed that the two strongest determinants of parent involvement in school, parental role construction and parent efficacy beliefs can be actively enhanced by schools. That is, schools’ ‘action (or inaction)’ influences parent involvement (Hoover-Dempsey et al., 2005, p. 123). Schools could generally do more to ensure that parent participation is systematic, integrated and sustainable (Epstein & Salinas, 2004; Mapp et al., 2008) and Weiss, Lopez and Rosenberg (2010) argue that school improvement that is truly inclusive of parent perspective must rely on something more coordinated than the 'random acts of involvement' that characterise most school strategies and practices (p. 1).

Schools tend to measure parental interest through physical presence (Goodall, 2013), but parent engagement in education is not always as visible as involvement and it might go unnoticed (Hoover-Dempsey et al., 2005). Teachers might, in fact, believe that parents who volunteer value education more than those who do not, regardless of the ways in which these parents might support and value their child's education at home (Hill & Taylor, 2004; Muller, 2006). Most parent involvement tends to be at the initiation of the school (Goodall, 2012; Mapp, 2004) and parent decisions to become involved depend on the degree to which they feel invited and welcomed into their child's school (Fishman & Nickerson, 2015; Jennings & Bosch, 2011; Hoover-Dempsey et al, 2005).

Henderson, Mapp, Johnson and Davies (2007) developed a typology of invitation and welcome, and willingness to share power with parents associated with four 'types' of school – the *partnership school*, the *open-door school*, the *come-if-we-call-you school* and the *fortress school*. The most welcoming schools, *partnership schools*, have permeable boundaries between school, families and community and welcome parents as part of the decision-making process. At the other extreme, *fortress schools*, as the name suggests, hold tightly to power and decision-making processes and perceive the functions of family and school to be separate responsibilities. Epstein (2010) conceptualises the opposing ends of the continuum of parent-school relationships as 'overlapping' and 'separate spheres of influence' (p. 82): successful parent-school relationships are partnerships that locate the student at the centre of a culture of care and encouragement (Brooker, 2010; Epstein, 2010). In such partnerships, school and family each recognise that they are 'overlapping', not 'separate spheres of influence' and promote the other's efforts for the child's overall wellbeing and success (Epstein, 2010, p. 82). From an ecological systems perspective, student achievement and school improvement result from the interactions between the overlapping systems of home and school rather than being attributed to either school, individual student ability or family circumstance.

### 2.8.3. Barriers to involvement and engagement

*Parent factors such as socio-economic status, race, ethnicity, and level of education present barriers to involvement and engagement*

Pushor (2013) suggests that effective parent engagement not only honours ‘teachers and the purposes of schooling’ but also honours ‘parents and the essence of what families are about’ (p. 7). However, the values promoted and held by schools might not always be consistent with the values of parents (Harris & Goodall, 2007; Woodrow et al., 2016) and, in many cases, schools hold family life, including an appreciation for the family’s social status and cultural heritage, at a distance (Pushor, 2013).

Parent involvement and engagement – and school invitations to become involved – are related to social capital. The parent’s socio-economic or employment status and level of education determines the degree to which they fit into, understand and question the predominantly middle-class culture of a school (Bagnall et al., 2003; Gillies, 2006; Goodall, 2012; Higgins & Morley, 2014). It has been argued that the capacity for parents to navigate the school context is determined by educators’ efforts to defend the dominant culture of the school and distance parents through professional knowledge (Hill & Tyson, 2009; Pushor, 2012; Scorgie, 2015).

### 2.8.4. Student factors and parent involvement and engagement

*Student factors such as learning, social-emotional or behavioural disabilities present barriers to parent involvement and engagement*

Woodrow and colleagues (2016) found that parents of SEN students and educators share similar attitudes around the importance of learning. While this group of parents appreciate the challenges of inclusion and have ‘realistic expectations of the outcomes of learning’ for their child (p. viii), the authors found that, in focusing on gaining accurate assessment and adequate support for their child, these parents’ efforts to participate in their child’s education brought them into conflict with educators (p. 62).

Parents of children with identified disabilities are central to their child’s inclusion at school, however, successive reviews of the Disability Standards for Education 2005 (Deloitte, 2017) and a recent parent survey by CYDA (2017) indicate that Australian parents are not fully aware of their child’s rights, of the supports available to their child, or of their own role in their child’s inclusion. In the Australian and international literature, parents frequently report a lack of consultation about their child’s inclusion and perceive that a favour has been extended rather than a right acknowledged (DSS, 2009; Gillies & Carrington, 2004; MacLeod et al., 2017; Norwich, 2013; Robinson & Truscott, 2014).

Parents of neurodiverse children are the mediators between home, school and medical, mental health and allied health professionals and they often initiate, and usually negotiate, the rounds of consultations that eventuate in a diagnosis (Mitchell, Morton & Hornby, 2010; Scorgie, 2015). Parents feel a sense of responsibility to do this when confronted by school inaction (CYDA, 2016; Mattson & Roll-Pettersson, 2007), and then play an intrinsic role in managing their child’s therapeutic interventions (Joosten & Safe, 2014). Bourke-Taylor and colleagues (2010) indicate that, from the point of diagnosis, neurodiverse children and their parents commence a ‘lifetime of professional services that seek to optimise the child’s health, development, education and participation in the community’ (p. 127). While disability policies identify supports that are potentially available in schools, research indicates that access is not always consistent, timely or available (de Boer et al., 2011; Mitchell et al., 2010; Trétault et al., 2014). This places the responsibility on parents to either advocate for services within the school system or to seek private professional advice and support (Cologon 2013; Delaney, 2017; Runswick-Cole, 2008). Either option, which Green (2001) identifies as 'crucial to attaining a normalised lifestyle' for parents of SEN children (p. 801), can be expensive and/ or exhausting as parents often struggle to understand the complexities of diagnosis and remediation strategies (Bourke-Taylor et al., 2010). Reupert, Deppeler and Sharma's (2015) research into the perspectives of parents of children with ASD identified a need for schools to act as 'catalyst points' for government agencies and interventions. This speaks to a broader conception of 'inclusion' that assists parents to positively engage in their child's education (Norwich, Griffiths & Burden, 2005).

Parents of SEN students report feeling marginalised by education professionals at their child's school, and this is particularly true if their child's learning, social or behavioural difficulties are viewed as problematic by their child's classroom teacher. Parents of neurodiverse children report feeling criticised and negatively judged as parents (Broomhead, 2013; Gwernan-Jones et al., 2015); that their expert parent knowledge was ignored (Reupert et al., 2015); and report that teachers often fail to understand their efforts to understand their child's difficulties and access intervention (Gill & Liamputtong, 2009; Norwich et al., 2005).

Parent motivations for involvement are not just influenced by parent cognitions and role construction, but by their own personal experiences and histories (Posey-Maddox & Haley-Lock, 2016) and by their sense of connectedness to the wider school community (Dove, Zorotovich & Gregg, 2018). Research indicates that parent insecurity about their child's level of peer acceptance might affect their own capacity to develop supportive relationships with parents of developmentally typical students (Scorgie, 2015) or with educators and school leaders (Auerbach, 2007).

### 2.8.5. Attitudes of education professionals

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*Professional attitudes present barriers to parent involvement at school*

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Saltmarsh, Barr and Chapman (2015) suggest that, while pre-service education programs are preparing graduate teachers for positive relationships with parents, there is a need for ongoing professional development. These findings validate Doecke, Parr, Rennie and Williams' (2008) study in which 82% of Australian teachers felt that developing 'parent and community involvement' was an area of 'overwhelming need' that was not being met by professional development opportunities (p.88). However, parents and teachers share different perceptions of what constitutes 'involvement' (Curry & Holter, 2019; Ferrara, 2009), especially in areas such as school decision-making and governance (Povey et al., 2016).

Australian and international research indicates that school leaders and experienced teachers have ambivalent attitudes towards the extent of parental involvement (Macfarlane, 2009; Povey et al., 2016) and tend to have a 'school-centric' view that focuses on inviting parents to physically attend the school for events (Posey-Maddox & Haley-Lock, 2016) or to become involved in volunteering activities (Ferrara, 2009). In recent years, there has been increasing concern about the overinvolvement of affluent, urban middle-class parents (Hornby & Blackwell, 2018) and this is partly based on professional awareness of the negative impacts of overinvolved parenting on adolescent self-efficacy and independence (Reed, Duncan, Lucier-Greer, Fixelle & Ferraro, 2016; Segrin et al., 2015). It is reinforced by the negative public discourse that holds 'helicopter' and 'snowplough' parents responsible for the creation of a 'bubble-wrap' or 'snowflake' generation lacking resilience.

However, concerns about 'overinvolved' parents also relate to what Pushor (2012) describes as the 'school as *protectorate*' mentality among educators who seek to protect their professional domain by marginalising (sometimes unconsciously) the role of parents at school. Grolnick (2014) argues that schools do not always try to understand why parents become involved; and parents of neurodiverse children may become highly involved, to the point of advocacy or conflict, when they perceive that their parent expertise is ignored (McLeod et al., 2017; Porter et al., 2013; Tucker & Schwartz, 2013; Zaretsky, 2005); that the school does not communicate effectively about their child (Stokes & Macfarlane, 2011); that their child's needs are not being met by the school (AFDO, 2013; Lake & Billingsley, 2000); or when they have concerns about their child's inclusion (AFDO, 2013; Cologon, 2013; Deloitte 2017; Earey, 2013).

### 2.8.6. Relational trust

*Parent involvement in schools depends on relational trust in teachers and leaders*

Relational trust is the foundation of effective and productive parent-school partnerships (Goddard, Tschannen-Moran & Hoy, 2001), or as Bryk and Schneider (2003) describe it, 'the connective tissue that binds individuals together to advance the welfare and education of students' (p. 44). These authors conceptualise trust as having four components: respect, competence, integrity and personal regard. Parent trust in schools develops when teachers and principals demonstrate that they value their students; are able to perform their specific pedagogical and leadership roles; act in accordance with espoused beliefs; and care for their students.

In general, parent trust in schools is initially based on a symbolic or 'proxy' trust in the institution, however, that trust is only sustained by the teachers' and leaders' 'demonstrated competence and integrity' (Kochanek, 2005, p. 13). This is especially important for parents of SEN students, who are anxious about their child's vulnerability in the school environment (Stoner & Angell, 2014). Angell, Stoner and Shelden (2009) found that mothers of SEN students described an implicit level of trust in their child's school that was broken only by issues relating to their child's care. Their research, as well as studies conducted by Shelden, Angell, Stoner and Roseland (2010) and Stoner and Angell (2014), indicates that parents of SEN students perceive specific school and educator characteristics that either facilitate or diminish trust. These included a 'nonjudgmental' school climate that focused on children's successes; staff knowledge about their children's disabilities, or a willingness to learn; a flexible attitude to teaching approaches and modifications; and including parents as part of a team dedicated to their child (Angell, Stoner & Shelden, 2009, p. 171).

Parents value principals and teachers who demonstrate authentic caring, that is, who view students as ‘individuals first and their disabilities as part of, but not the prime components of, their personalities’ (Angell, Stoner & Shelden, 2009, p. 166; see also Shelden et al., 2010). Teachers demonstrate authentic caring through communication: when teachers actively listen and appreciate the parent’s perspective, parents are more inclined to trust them (Stoner & Angell, 2014). Parents initiate communication with teachers to pass on their own parent knowledge about their child; failing to follow up on or ignoring parent communication diminishes trust and results in more persistent and increased communication attempts from parents.

### 2.8.7. The transition to high school

*Parent involvement declines as children transition to high school*

Parent trust in schools diminishes as children transition to high school – Adams and Christenson (2000) suggest that this is related to the difficulties attending authentically caring relationships between teacher and student and increasing expectations around student independence that lessens communication with parents. The authors also suggest that declining parent involvement diminishes teacher trust in parents, which then reduces parents’ willingness to become involved.

On the whole, parents are less involved in school during the high school years (Jensen & Minke, 2017) and recent Australian research demonstrates a significant decline in parent support in early high school, and then again after Year 10 (C.E.S.E., 2018). Continued parent support throughout the transition to high school can help students develop social and emotional skills that buffer students from the academic as well as the social challenges of transition (Benner et al., 2017; Mackenzie, McMaugh & O’Sullivan, 2012; Waters et al., 2014). However, parents feel less capable of helping their child as work becomes more specialised and difficult during high school (Goodall, 2012; Hoover-Dempsey et al., 2005; Peters et al., 2008). For the reasons outlined in section 2.6, *The school microsystem*, parents of SEN students have significant concerns about their child’s transition to high school (Fortuna, 2014;

Jindal-Snape et al., 2005; Reupert et al., 2015) and generally want to be more fully informed about, and included in, their child's transition process (Tso & Strnadová, 2017).

## 2.9. **The parent exosystem**

As indicated above, there is an extensive field of literature demonstrating the importance of authoritative parenting for child and adolescent development, and the positive impact of effective parent-school relationships on children's educational outcomes. In terms of child development, families matter and so do the interactions that occur within the family microsystem. This research evidence underpins Australia's current federal and state policies relating to families, student engagement and wellbeing, and the inclusion of students with disability.

These policies are predicated on the established connection between parental and child wellbeing (Adema, 2012; Daly et al., 2015), and between family disadvantage and child developmental outcomes (Warren & Edwards, 2017); and represent a general trend of government incursion into the once private arenas of family and parenting (Rake et al., 2011; Social Policy Research Centre, University of New South Wales [UNSW], 2010). They also represent a Foucauldian concept of 'governmentality' (Foucault, 1994), that is, the family ecology offers a unique opportunity for government agencies to encourage parenting in the direction of officially sanctioned and desired behaviours, and to create the conditions that promote positive child and adolescent development (Daly et al., 2015; Davies & Bansel, 2007; Hopwood & Clerke, 2016). In this respect, government expenditures on interventions that support families are viewed as investments in the nation's 'human capital' assets (Hollonds, 2016; p. 2). Blaming parents or 'interfering in family life' might not be intentional (Hollonds, 2016, p. 3), yet family policies undoubtedly create a perception of 'correct' parenting that is linked to family income, parent education and marital status (Gilles, 2008; Miller, 2017). There is also a tension between expert perceptions of parenting as a set of evidence-based skills and practices that can be systemically supported and that have collective benefits for society; and widespread perceptions of parenting as something that is innate, is best supported through parent social and kin networks and that only affects the immediate family and child (Volmert, Kendall-Taylor, Cosh & Lindland, 2016).

Current federal and state education policy settings recognise the importance of stakeholder consultation (Deloitte, 2017; Matters, 2018); acknowledge that parents should occupy a more active role in their children's education; and recognise that the parent-school relationship should be more than that of 'bystander' and 'professional' (O'Hehir & Savelsberg, 2014). This represents a conceptual shift from viewing the lifeworlds and responsibilities of parents, professionals and government as separate, to a more ecological perspective that sees the responsibility for children's development and education as shared between teachers and parents, with government support (Epstein, 2013).

These issues are reflected in the rhetoric of 'parent and community engagement', and parent-school 'partnerships' and 'collaboration' that pervades federal and state education strategies to strengthen school success. Federal strategies include the *Family-School Partnership Framework* (DEEWR, 2017), the *National School Improvement Tool* (Australian Council for Educational Research (ACER), 2016), and the *Australian Student Wellbeing Framework* (Education Council, 2018). At a state level, the concept of parent-school partnerships underpins Queensland's education policy framework. 'Partnering for Success' is a key principle of the *State Schools Strategy 2019-2023* (Department of Education, 2019b), and this is clarified in the *Parent and Community Engagement Framework* (PACE) (Department of Education, 2013). The five dimensions of the PACE framework – inclusive communication; partnerships with parents to promote learning and wellbeing; school and wider community collaboration; involvement of parents, students and community in decision-making; and respectful school cultures each link to dimensions of the *National School Improvement Tool* (ACER, 2016). In the same way that policy settings for children's wellbeing and inclusion lack cohesion, this appears to be an isolated example of alignment between state and federal policy contexts, when the national policy context has been described as otherwise 'fragmented' (UNSW, 2010, p. 60; see also AIFS, 2016).

These concerns persist; ahead of the 2019 federal general election ARACY released a policy 'wish list' intended for the incoming government. At the top of this list, ARACY (2019) advocated for a cabinet portfolio dedicated to the wellbeing of Australia's children and to the 'alignment of policy settings, service delivery and effort across Commonwealth agencies and other jurisdictions' (p. 2); and to ensure rhetoric becomes reality for Australia's children and parents. While ARACY acknowledged that Australia's policy settings are based on extensive evidence demonstrating the importance of 'supporting parents in their parenting role', the organisation pointed out that there are 'significant gaps in our knowledge about the real-world experiences of today's parents' (p. 5) which will impact the development of effective future policy. The current study aims to contribute to this knowledge gap.

Policies relating to the inclusion of SEN students, previously identified in Section 2.3 *The adolescent's policy exosystem*, articulate and value the role of parents in their child's education. However, parental uncertainties around their role and position largely relate to discrepancies in home-school communication (Goodall, 2016; Meier & Lemmer, 2015); and a lack of clarity around exactly what constitutes parent involvement in school or engagement in education (Goodall & Montgomery, 2014; Jennings & Bosch, 2011; O'Hehir & Savelsberg, 2014).

## 2.10. **The parent macrosystem**

The parent macrosystem is determined by the confluence of ideas about childrearing practices and the role of parents, specific to the late 20th and early 21st centuries, that constitute dominant ideologies of contemporary parenting. The literature suggests that demographic and institutional change, and economic globalisation have contributed to a culture of contemporary child-rearing that is radically different to previous generations of parents (Miller, 2017). This literature also suggests that ideologies of contemporary parenting make parents responsible for their child's developmental outcomes, regardless of social disadvantage or poverty (Furedi, 2009, 2018; Lareau, 2002, 2011); are underpinned by neoliberal ideas of market-driven consumerism and competition (Savage, Sellar & Gorur, 2013; Vincent & Ball, 2007); and are shaped by the increasing intrusion of state authority into family life (Gillies, 2008). This reframes childrearing into an area of expertise determined by experts and according to middle-class values (Bagnall et al., 2003; Holloway & Pimlott-Wilson, 2014; Lee, 2014).

Research into contemporary parenting suggests that it is: ‘knowledgeable’ (Aarsand, 2014) and ‘expert-led’ (Smyth, 2014; Wall, 2010); ‘paranoid’ (Furedi, 2018), ‘risk-averse’ and ‘anxious’ (Barr et al., 2012; Stearns, 2004); and ‘overinvolved’ (Segrin et al., 2015; Padilla-Walker & Nelson, 2012). This adds up to a pervasive conception of contemporary parenting as ‘data-driven’ (Smyth, 2014); ‘relentless’ (Miller, 2018); child-centred and ‘intensive’ (Faircloth, 2014; Hays 1996; Smyth & Craig, 2017).

Policies relating to effective parenting practices and optimum parent involvement in school address ‘parents and carers’ and are positioned within broader constructions of what it means to be a ‘good’ parent (Craig, Powell & Smyth, 2014). However, policy rhetoric, suggests Miller (2017) ‘glosses over deeply embedded gendered differences and histories’ that influence how mothers and fathers share and divide parenting responsibilities and labour (p. 2). Indeed, Blum (2007) suggests that in family and parenting policy rhetoric, ‘parent’ is a euphemism for ‘mother’. Research studies and Australian statistical data suggest that, despite significant social shifts in fathers’ engagement in family life (Craig et al., 2014), it is mostly mothers who take responsibility for matters of childcare and family-school interactions (AIFS, 2016; Baker & Drapela, 2010; Miller, 2017) and they do so in accordance with public constructions of appropriate childrearing practices and ideologies of ‘good’ mothers (Henderson, Harmon & Newman, 2015; Pedersen, 2016; Romagnoli & Wall, 2012).

As indicated in Chapter 1, in an atmosphere of uncertain economic futures and highly competitive educational settings, parents feel increasingly responsible for their child’s future success and expend considerable resources to stack the academic and cultural deck in their child’s favour (Barr et al., 2012; Vincent, 2017). For most Australian families, decisions around their child’s education are determined by the compulsory nature of school attendance (Toumbourou et al., 2014) and by demographic factors such as household income and location (Warren, 2016). However, 40% of Australian students are enrolled in independent schools, compared with an OECD average of 18% (ABS, 2017) and home schooling via distance education is an increasingly popular option (ABS, 2017). These enrolment patterns indicate that parents consider the importance of a tailored education (Vincent & Maxwell, 2016; Warren, 2016); and finding the right ‘fit’ between child and school.

Volmert and colleagues (2016) found that, while parenting experts identify the link between child characteristics and parenting behaviour, this is not a factor in the way the Australian public thinks about or understands parenting. In other words, people tend to have a default view that parenting is a ‘one-way’ process that constitutes something parents do to a child, and do not consider the impact an individual child might have on a parent’s capacity to conform to expectations of ‘good’ parenting (pp. 7-8). This has important implications for the way people view the parenting behaviours of parents of neurodiverse children, who often struggle with the stigma associated with their child’s learning, social or emotional difficulties (Farrugia, 2009; Francis; 2012 Lalvani; 2015). As Vincent (2017) argues, ‘a particular public ferocity is retained for women who ‘fail’ their mothering responsibilities’ (p. 546).

Although neuroscience provides an ‘excuse’ and explanation for their child’s difficulties and difference, mothers of children with invisible disabilities are still blamed and held responsible by others for their child’s public behaviours, which are seen to reflect on their mothering abilities (Courcy & des Rivières, 2017; Farrugia, 2009; Gray, 2002; Russell & Norwich, 2012). In seeking support for their child, their version of ‘intensive mothering’ intensifies – they fight for services (Safe, Joosten and Molineux, 2012); advocate to the point of activism (Boshoff et al., 2016; Good, Hollis-English & Attwell, 2017) and become ‘vigilantes’ (Blum, 2007). Blum (2007) sees this as something like ‘concerted cultivation’ (Lareau, 2002, 2011) but more exaggerated and in response to ‘authoritative discourses’ about disability and ‘appropriate’ mothering (p. 222). In the absence of viable alternatives, these mothers take on the responsibility for hyper vigilance and ‘intensive’ care to the exclusion of other roles (Ryan & Runswick-Cole, 2008). They are involved in their child’s life as apprentice co-therapists (Blum, 2007; Safe et al., 2012); negotiators and coordinators of services (Delaney, 2017); and protectors of their child from outside scrutiny and criticism (Woodgate, Ateah & Secco, 2008). Russell and Norwich (2012) suggest that this high level of involvement is an extension of the ‘good parenting narrative’ (p. 238) – this is what it takes to do the best for their child.

## 2.11. **Conclusion**

This chapter depicted, in broad brush strokes, the picture created by current research of what school is like for neurodiverse adolescents, and of the proximal and distal settings that influence their education. It is not a particularly comforting picture: although student wellbeing and engagement in school are Australian educational priorities, there is a gap between rhetoric and day-to-day schooling practice. The gap is created by the attitudes of teachers and other students towards, and understanding of, neurocognitive difference and mental health; by education resourcing and funding models; and by the pressures of standards-driven education practices. As a result, neurodiverse students fall into this gap more often than not. Their different abilities place them at a disadvantage in so many of their interactions in the school context, and this has a cumulatively negative impact on their current well*being* and future well*becoming*. This broad research picture also shows what it is like for their parents, who experience their child's difficulties vicariously, and experience their own difficulties in the parent-school relationship. The overall message is that supporting their child in the immediate settings of home and school is primarily a maternal responsibility that is demanding of time, resources and emotional labour.

There is a need for studies that fill out the picture of these adolescents' and parents' lifeworlds and the next chapter explains the research approach that was adopted to approach this task. This IPA study is situated within the body of qualitative research which aims to understand the lived experiences of parents of children with disabilities from their own perspectives (Lalvani, 2011, 2015), and at an individual level (Kamenopoulou, 2016).

# CHAPTER 3: METHODOLOGY

## 3.1. Introduction

This chapter describes the research approach and methods chosen to examine the lived experiences of parents whose neurodiverse children experience anxiety related to the school setting. The chapter begins with a rationale for the use of Interpretive Phenomenological Analysis (IPA), given the inquiry focus and the researcher's paradigmatic assumptions (Lincoln, 2007; Rudestam & Newton, 2001). It then describes the theoretical background to IPA and goes on to describe the study's research procedures. These include: an outline of the research setting; strategies of gaining access to participants; ethical considerations; and procedures for data collection, analysis and presentation. The chapter concludes by discussing issues relating to research quality (Holliday, 2007).

## 3.2. Research paradigm

### 3.2.1. Inquiry focus

Submissions to the most recent Gonski review of Australian education (Gonski et al., 2018) expressed concerns over the question, 'How should school quality and educational success be measured?' because of its implied suggestion of a common understanding of 'school quality' and 'educational success', and that these concepts are quantifiable.

The question also demonstrates that while qualitative approaches to education research have flourished in the aftermath of the 'paradigm wars' (Gage, 1989; Lincoln, Lyneham & Guba, 2011), positivist quantitative research appears to provide a sense of certainty, and doubts linger over what counts as evidence in educational research, and what contribution qualitative research might make towards improving educational outcomes (Yates, 2004). These doubts have been revived by the proliferation of 'new paradigm' qualitative research approaches (Denzin & Lincoln, 2011) whose claims to legitimacy have not gone unchallenged by those who view the aims and procedures of the social and natural sciences as essentially aligned (Lather & St. Pierre, 2013). If the results of interpretive qualitative research were initially thought to be alarmingly unpredictable, many researchers interested in social inquiry have long felt that those methodologies have become safely mainstream and overly structured (St. Pierre, 2018). The field of post qualitative research demonstrates the continued development, in numerous directions, of social research inquiry. Post qualitative research – steeped in the theories of Foucault, Deleuze, Derrida and Guattari, among others, but unfettered by attachment to conventional methods of data presentation and analysis – presents a more diverse yet less certain way to investigate social issues (Delamont & Atkinson, 2004).

Chapter 1 advanced the notion that student social and emotional wellbeing is a critical and current concern; and Chapter 2 established the importance of inclusive school settings and effective relationships between schools and families for student wellbeing. Alongside existing quantitative research that measures ‘school quality’ and ‘educational success’ in terms of NAPLAN and PISA results sits the need to investigate the quality of schooling experiences (Cumming et al., 2018). Alongside existing quantitative research that measures the type and frequency of parent-school interactions, sits the need to investigate the quality of those interactions (Walker et al., 2005). And, given the focus on individual difference in inclusive education policy and practice, a need to foreground individual voices and perspectives (Kamenopoulou, 2016).

Qualitative research that focuses on people’s subjective experiences of everyday social phenomena, and that explores the meanings people assign to their experiences is not directed towards producing ‘hard data’ or generalisable findings (Creswell, 2009; Merriam & Tisdell, 2016). It is directed towards describing and illuminating the social world (Polkinghorne, 2005) and asks important, although essentially different, questions about that world, the interactions between its actors and the structure of its institutions (Holloway & Todres, 2007; Mason, 2017). Qualitative research interrogates common understandings of concepts such as ‘school quality’ and ‘educational success’; asking how individual educators, students and their families interpret these concepts.

This study’s concern with understanding individual parents’ subjective experiences was most consistent with a qualitative research approach. St. Pierre (2018) describes how the post qualitative researcher ‘does not know what to do first and then next and next’ (p. 604). While that describes many aspects of this study’s progress, I preferred the comfort of a research design in which I could ‘safely secure [my]self’ (St. Pierre, 2011, p.613) and looked to the more standard approaches, characterised by Brinkmann (2015) as ‘Good Old-Fashioned Qualitative Inquiry (GOFQI)’.

### 3.2.2. Characteristics of qualitative research

Qualitative approaches do not follow a common set of research processes or criteria but can be likened to a ‘complex, interconnected family of terms, concepts and assumptions’ (Denzin & Lincoln, 2005, p. 2). The extended family of qualitative methodologies shares a number of characteristics, all of which help the qualitative researcher understand the participants’ worlds and how they make sense of those worlds, but which also create issues of trustworthiness and validity (Merriam & Tisdell, 2016).

In qualitative research, claims relating to what is known to be real and true are founded on what the researcher observes, is told, interprets, and co-constructs with participants. While all researchers work within a theoretical framework, theory relating to qualitative research findings is built inductively from the data, and researchers must be careful to avoid shoehorning that data into external theories (Creswell, Hansen, Clark Plano & Morales, 2007; Merriam & Tisdell, 2016). As the researcher is the main instrument for data collection and analysis, qualitative research accepts the inevitable involvement of the researcher within the research process (Creswell et al., 2007; Denzin & Lincoln, 2013). However, the focus of the research is the participant’s perspective, so the credibility of findings depends on the disclosure of the researcher’s own values and beliefs (Creswell & Miller, 2000; Hurworth, 2008).

The naturalistic, social nature of qualitative research settings means that the research design must be flexible and responsive to any potential changes in that setting. The success of the research, therefore, depends on the openness of the researcher to alternative research directions rather than committing to a set route (Hurworth, 2008).

Lastly, qualitative research findings are represented as textual or visual depictions that use rich and expressive description and aim to build a detailed picture of the central phenomenon that resonates with the reader’s experience (Creswell et al., 2007; Merriam & Tisdell, 2016).

These aspects of qualitative research are consistent with the evolution and goals of the current study described in Chapter 1.

### 3.2.3. Methodological purposiveness and methodological congruence

The absence of a set of ‘neat, standard procedures’ (Hurworth, 2008, p. 5) to guide qualitative research means that qualitative researchers must make careful decisions about where to situate their research in an ever-increasing and evolving field of research options (Cunliffe, 2011; Lather, 2006; Lather & St Pierre, 2013).

There is no particular merit of one research approach over another, it is more important to consider ‘methodological purposiveness’ (Richards & Morse, 2012): the goodness of fit between the nature and purpose of the study and the selected research approach (Creswell, 2013; Merriam & Tisdell, 2016). The research question should be the starting point of the decision-making process about research methods, not the other way around (van Manen, 1990).

The choice of research approach should also reflect ‘methodological congruence’ (Richards & Morse, 2012): the correlation between the selected approach and the researcher’s philosophical assumptions about the nature of reality and knowledge (ontology and epistemology), the place of values in the research (axiology), the way in which research findings are represented (rhetoric), and the relationship between an overarching theoretical framework and the research methods (methodology) (Creswell et al., 2007; Lincoln, 2011; Mason, 2017).

Lincoln and colleagues (2011) propose that all researchers, regardless of the paradigm in which they work, are confronted with the same major issues: how they answer epistemological, ontological, axiological and methodological questions and how they align their position on these issues to develop internal coherence within their research. In reality, researcher beliefs exist on a continuum of paradigmatic assumptions, from subjectivist to objectivist (Cunliffe, 2011). Researchers must reflect on their orientation to each of these major issues to find a workable and consistent framework for their research (Creswell et al., 2007; Lather, 2006; Mason, 2017) whilst resisting the temptation to 'impose a single, umbrella-like paradigm over the entire project' (Denzin & Lincoln, 2011, p. xiii).

The starting point for this research, as outlined in Chapter 1, was my personal and professional interest in understanding the lived experience of parents whose neurodiverse children experience anxiety in the school setting. It is perhaps unsurprising that, given my personal, research and professional subjectivities identified above, during the process of narrowing the field of GOFQI, Case Study and Narrative approaches were considered as potential approaches to the research questions. Both are commonly used in educational research and have the potential to richly describe specific aspects of participants' lived experiences. With relevance to the current study, the National Mental Health Commission (2017) illustrated mental health issues with both personal narratives and case studies.

Case Study refers to both the research process and to the way the results are written and aims to develop an in-depth analysis of a particular case or set of cases (Creswell, 2013). Case Study typically uses a form of narrative, the vignette, to illustrate key themes within or across cases and is a foundational aspect of psychological practice and research that is interested in psychological and social phenomena. Case studies are commonly used to investigate social phenomena and issues in schools such as student behaviour, teaching practices and education policy (Mills, Durepos & Wiebe, 2010).

In previous research, I had used a Case Study approach to examine curriculum uptake by a group of teachers. However, in that situation the problem under investigation was well bounded in both physical, temporal and demographic terms. The issue under investigation leant itself to multiple data sources: on-site observation, interviews and curriculum frameworks. These are important aspects of Case Study research (Mills et al., 2010) but were either inappropriate to, or absent from, the current study.

In terms of research methodologies and methods of investigating social phenomena, Narrative inquiry is relatively new. However, humans have always told stories as a way of making meaning of their experience, as a way of living out their lives, and as a way of passing on culture and tradition (Clandinin & Rosiek, 2006). Narrative inquiry refers to both a specific methodology (Clandinin & Connelly, 2000) and to an umbrella approach for a wide rand of researchers, including post-modernists, phenomenologists, realists and social constructionists (Clandinin & Rosiek, 2006). With previous experience in conducting oral history and community history projects, I had long been interested in making meaning of the stories people tell about their lives. Approaching the participants' lived experiences via narrative was therefore familiar and comfortable and Narrative Inquiry was initially chosen as the research methodology for the current study. A significant part of this approach's appeal lay in the way researchers gain access to people's stories by 'coming alongside them', by 'living their lives with them'. Narrative Inquiry is 'research with' not 'research on' people (Clandinin, 2012).

The boundaries between qualitative approaches are often blurred and both IPA and Narrative Inquiry use the stories people tell to examine aspects of their lives as a given phenomenon (Clandinin & Connelly, 2000). There is a strong history of interpreting narrative within IPA research (Smith et al., 2009), but interpreting narrative is the means to an end. That is, IPA is interested in understanding the structure of the experience held in the narrative, rather than understanding the structure of the narrative itself.

Ultimately, the theoretical framework of IPA provided a structure that allowed for both investigation within and across cases and for the individual's narrative to be positioned in relation to the phenomenon (identified in Chapter 1) in question.

So, the research approach needed to allow for the exploration of the participants' lived experience and the meaning they attached to those experiences. The research approach also needed to accommodate my close and subjective interest in the central phenomenon and provide a means to acknowledge my own lived experience. This was 'emotionally engaged research' (Campbell, 2002; Dickson-Swift, James, Kippen & Liamputtong, 2009); my personal parenting experience and the fact that the participants shared their stories as an act of trust and hope gave me a sense of great responsibility. During the course of the research it became important to me that the participants' voices were not fractured and disembodied within the eventual research text (Schratz, 1993). And, in deference to the participants' expert parent knowledge

(Pushor, 2012), it also became important that the participants felt they had a say in the direction of the research (Somekh et al., 2005).

The study, therefore, required a reflexive and interpretive research framework that would make the participants' lived experiences tangible to the reader; that accounted for my personal investment in the research problem; and that allowed for a dialogue between the 'empathic gaze' of the researcher-as-parent and the 'suspicious gaze' of the researcher-as-educator (Larkin, Eatough & Osborn, 2011; Ricoeur, 1970; Smith, et al., 2009; Yardley, 2000). Lather (2006) has argued that if the interpretivist paradigm were 'a public event, it would be a community picnic (cooperative, interactive, humanistic)' (p. 38); a description which suited how I envisaged this study.

To some extent, these subjectivities conflicted with my original research background in political history. My 'historian-self' valued objectivity and distance from a phenomenon, something that was clearly impossible in the current study, given my personal experience. Then there were inherited familial values; I grew up around the belief that investigations into social worlds should involve as many controls as possible and, given the unreliability of humans (no irony intended), social research was inherently suspect and held less value than 'real' scientific inquiry. Looking back on inconsistencies in my thesis proposal, I can see a struggle between tacitly held ideas about validity and generalisability, and what I perceived to be a necessary research focus. My onto-epistemological starting point was therefore not one of happy conviction; while I leaned towards the perspective that mixed-methods research offered the best of both worlds, I had committed to a naturalistic paradigm. An unforeseen delay in data gathering provided the reflective space necessary for a 'subjectivity audit' (Peshkin, 1988, p. 18). The results of that audit recalled the earlier research training and inherited values identified above, affording insight into the gap between paradigmatic and personal beliefs and assumptions, and enabling me to develop a methodological wish-list with more certainty.

As an interpretive approach, focused on the essential themes of participants' lived experience, hermeneutic phenomenology offered possibilities in addressing the research question (Gill 2014; Hurworth, 2008). However, this study was founded in valuing the participants' individual experience, so it needed to explore what was both unique *and* shared. And the study aimed to inform educational practice, so the research approach needed to allow for the type of ‘transferability of meaning’ developed in Refractive Phenomenology (Abawi, 2012) to ensure that the significance of the study’s outcomes was contextualised within the extant body of literature on parent-school relationships. Interpretive Phenomenological Analysis (IPA) accommodated these research criteria.

### 3.2.4. Specific qualitative approach: Interpretive Phenomenological Analysis

Interpretive Phenomenological Analysis (IPA) (Smith, 1996, 2004, 2011; Smith, et al., 2009) is an eclectic, phenomenological and interpretive approach to social research; with an idiographic commitment to understanding individuals’ lived experience (Palmer, Larkin, de Visser & Fadden, 2010; Smith, et al., 2009). IPA has asked, ‘what is this experience like for this person?’ in the fields of health science, branches of psychology, organisational behaviour and education (Brocki & Wearden, 2006). Relevant to the broad themes of this research study, IPA studies have examined the perceptions of young people with autism (Huws & Jones, 2008); parenting and parental experiences (Glasscoe & Smith, 2011; Jordan, Eccleston & Osborn, 2007; Schweitzer, Griffiths & Yates, 2012 ) and the impact of maternal depression on families (Van Parys, Smith & Rober, 2014).

As a phenomenological approach to inquiry, IPA is interested in the essential elements of participants’ ‘personal and social worlds’ (Smith & Osborn, 2003, p. 53) and is based on an eclectic interpretation of existential phenomenology (Smith et al., 2009).

As an interpretive phenomenological approach, IPA is concerned with understanding the participant’s lived experience from the perspectives of both the participant and the researcher, and draws on the hermeneutic principles of Schleiermacher, Heidegger and Gadamer (Smith, 2007; Smith et al., 2009).

Finally, IPA’s origins and interest in psychology have informed its idiographic focus. In developing IPA, Smith (1996) advocated a qualitative approach to psychology that focused on making particular, rather than nomothetic claims about an individual’s experience. That is, IPA focuses on the meaning of an experience for a given person (Smith, 2011; Smith et al., 2009).

IPA's central concern, then, is with understanding individuals' subjective experiences of aspects of their world; that which Husserl called the 'life-world' (*Lebenswelt*)' (Moran, 2000, p. 9). This includes both the everyday world that generally escapes reflective notice as well as more significant experiences and events that prompt the individual to 'contemplate, take stock, worry, and try to make sense of what is happening' (Smith et al., 2009, p. 188).

Because 'there is no clear and unmediated window' into that world (Eatough & Smith, 2006, p. 485), IPA's mechanism for getting as close as possible to participants' personal perceptions, and understanding the key elements of their experience lies in its adoption of the phenomenological method and a double hermeneutic process through which 'the participants are trying to make sense of their world … [and] the researcher is trying to make sense of the participants trying to make sense of their world' (Smith & Osborn, 2003 , p. 51).

### 3.2.5. Philosophical assumptions of IPA

IPA is both method and methodology, grounded in a phenomenological epistemology (Osborn & Smith, 2008; Smith, Jarman & Osborn, 1999). Derived, as they are from the European tradition of philosophical inquiry into consciousness and existence, IPA's theoretical underpinnings are complex – the following outline of IPA's theoretical foundations is therefore a brief overview of the key themes central to any IPA project:

*Lived experience*: IPA asks, 'How do we get close to participants' lived experience and how do we justify any knowledge claims relating to their accounts?' and bases this inquiry in European phenomenology.

*The meaning people assign to their lived experience*: IPA turns to hermeneutics to respond to the question, 'How do we interpret meaning, from the perspective of participant *and* researcher?' This emphasis is a key defining feature of IPA – in traditional phenomenology the researcher's written account is a descriptive account 'not explanation or analysis … In other words, (Heidegger's words) the expression 'descriptive phenomenology' … is at bottom tautological (Being and Time, 59)' (in Glendinning, 2007, p. 39).

*The lived experience of a particular individual and shared experiences*: IPA's priority is to establish patterns within an individual's experience, in a specific context, before 'cautiously' connecting patterns and themes across the study participants' shared experiences (Smith et al., 2009). IPA research focuses on interpreting the meaning individuals assign to their experiences and in understanding 'what it is like to be experiencing this, for this particular person, in this context' (Larkin et al., 2011, p. 10). While, the narrative produced from a traditional phenomenological inquiry aims to 'let things speak for themselves' (van Manen, 1990, p. 180), IPA situates the researcher's interpretive account within the wider context of research literature relevant to the research findings (Smith et al., 2009).

In the context of IPA studies, the use of the term 'narrative' is used in the sense of meaning-making and 'world making' (Bruner, 2004, p. 691). Bruner (2001) contends that the stories people tell about themselves are exercises in 'self-construction': people make sense of their experiences and communicate their life stories through narratives. IPA is interested in the experience, and interpretations of experience, that is revealed by narrative; that is, the focus is on the narrative's content, rather than on its structure or language features (Smith et al., 2009).

#### 3.2.5.1. IPA as a phenomenological approach to researching lived experience

Moran (2000) describes phenomenology as a way of '*doing* philosophy' [emphasis added] which 'emphasises the attempt to get to the truth of matters, to describe *phenomena*, in the broadest sense as whatever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experiencer' [emphasis in original] (p.4). Phenomenology is also a social research method which examines the meaning of lived experience and aims to '[bring] us in more direct contact with the world' (van Manen, 1984, p.1).

Phenomenology should not be seen as a 'unified theory' but rather as a 'movement', popularised by twentieth century European philosophers, that encompasses numerous schools of thought and approaches to research (Larkin et al., 2011, p. 5; van Manen, 2011). However, phenomenology does have a central concern, which is understanding the underlying structures of the everyday lived experiences of humans in the world; and this is based on the understanding that perceptions and appearances of the world should be taken as evidence of the world. Phenomenologists are interested in the way that, in the course of our everyday experience of the world, we encounter and make sense of all the entities (objects, structures, other people and living things) which make up our world.

Different phenomenological approaches adopt different methods for gaining traction on lived experience and have different perspectives on the position of subject and object, knower and known. As an eclectic approach, IPA draws on the transcendental phenomenology of Edmund Husserl, the hermeneutic and existential phenomenology of Martin Heidegger and the embodied phenomenology of Maurice Merleau-Ponty. Given the complexity of their respective ideas and the extensive body of literature devoted to elucidating these ideas, this section will provide only a brief overview, with a focus on their contribution to IPA.

Husserlian phenomenology focuses on the question of how we come to understand our own experience of a phenomenon and, having done so, how we identify the *essential* elements of that phenomenon; the features and structures that make it *this* experience or object or relationship and not another type of experience or object or relationship (Smith et al., 2009). In other words, how we might discover and capture the 'is-ness' of a given phenomenon (Finlay, 2014, p. 121). The fundamental characteristic of phenomenology is to 'describe how the world is constituted and experienced through conscious acts' (van Manen, 1990, p. 184). When Husserl urged us to 'go back to the things themselves!' (in van Manen, 1990, p. 184), he was referring to the experiential content of consciousness.

According to Cartesian dualism, consciousness is subjective and not part of the physical world – it cannot be directly observed or measured or sensed so we can never know if our mental content, that is, the objects of our consciousness, exist independently of how we experience them (Searle, 2013). From this perspective, examining subjective experience is problematic. And yet, as Husserl emphasised, consciousness is a pre-condition for knowledge – our consciousness constitutes the world of objects (Moran, 2005). Husserl's phenomenological method, known as transcendental phenomenology, provides a means to examine the way in which the mind constitutes phenomena and makes it possible for us to experience them as objects, so that they transcend our own consciousness (Wrathall & Dreyfus, 2006).

For Husserl, consciousness, or perception, or awareness must always be consciousness or perception or awareness *of* something: consciousness is always directed so that I am aware *of* another person; I feel an emotion (anger, love etc) *about* that person. Husserl called this directedness *intentionality* (Dreyfus, 1978; van Manen, 1990), which, he argued is the ‘‘essential character’ or ‘universal fundamental property’ of our mental life’ (Moran, 2005, p. 4). For Husserl, phenomenological inquiry is an attempt to capture the intentional act, to understand the directedness of consciousness and to understand the intentional relationship between consciousness and the objects of our lived experience (Moran, 2005; Mulhall, 2014; Smith et al., 2009).

Importantly, Husserl’s belief, that intentionality is an act of consciousness directed towards something, has epistemological implications and thus made the dualism of subject-object beside the point (Creswell, 1998; Larkin et al., 2011). If I am able to experience something in the world, to perceive something because my conscious mind is directed towards it, then, by virtue of the way it appears to my consciousness, I am able to describe it as an object (Moran, 2005). The key importance for IPA studies is that our perceptions of lived experience can be taken as evidence of that experience. As Bruner (2004) suggests, there is no such thing as ‘‘life itself’ outside of what we selectively recall from memory, observe, interpret and narrate’ (p.692).

The main challenge for the process of phenomenological inquiry, according to Husserl, is that when we are involved in our normal, everyday world we are not fully aware (or conscious) of aspects of that experience. Objects in our everyday life and our everyday surrounding world present as obstacles that prevent us from being able to examine the contents of our conscious experience (Smith et al., 2009). Husserl believed that the assumptions and preconceptions that constitute our *natural attitude* get in the way of our ability to properly see the object in itself (Smith et al., 2009). And when we are immersed in the stream of our everyday subjective experience, our *lifeworld*, we engage with objects as existing things but do not reflect on their significance or properties.

For example, within the parent-school relationship there are countless objects, actions and relationships, but a simple and universally familiar object is the school gate. All schools have one or more points of access but usually only one main, designated entrance. Within a parent's natural attitude towards a given school gate there will be the taken-for-granted things that we know about gates (their general purpose, structure, materials and mechanisms); there will be the additional, specific things we know about this gate (the school rules around pick-up/ drop-off); and there will be the assumptions, values and beliefs that we attach to it based on our own previous schooling experiences and our current experiences as the parent of a child who attends this school. These may be positive (the gate is protective – it keeps our children safe within) or negative (the gate is excluding – I am not part of the school community). For most of the time, however, the gate just *is* – it is an unexamined aspect of our everyday world.

Putting aside the *natural attitude* requires a process of reflection and suspension of judgement (or *bracketing*) so that we might examine and describe the structures of our experience. The *phenomenological attitude* permits an unprejudiced investigation of the phenomena of lived experience (Finlay, 2014) which might reveal, for example, the meaning the school gate holds for a parent after their child's suspension from the school.

This reflective process, which Husserl called the *epoché*, is the first in a series of *reductions*, 'not a reducing *down*, but a leading *back*—to the phenomena' [emphasis in original] (Larkin et al., 2011, p. 5), where the ultimate objective is to understand what is at the heart of an individual's experience of a phenomenon, that is, to discover (as a kind of uncovering) the 'essence' or '*eidos*' or 'idea' of a phenomenon (Smith et al.,2009, p.14). Husserl's phenomenology asks for the very nature of a phenomenon, for that which makes a 'thing what it *is* (and without which it could not be what it is)' (Van Manen, 1984, p. 1). Through an intuitive and imaginative process of examination and writing, the writer arrives at the invariant structure or essence of an experience (Creswell, 1998).

While IPA is based on the fundamental concepts of Husserl's philosophy, it has a different view (Heidegger's view) of bracketing and takes an entirely different attitude, influenced by its idiographic focus, towards the concept of invariant structure or 'essence' (Smith et al., 2009).

Heidegger's view on bracketing relates to his argument that suspending subjectivity is not possible; all inquiry into phenomena is necessarily interpretive because we are always in the world. For Heidegger, Husserl's approach to phenomenology missed the point; knowledge of an objective world was not the question. Rather, the point, the fundamental question relates to 'what *is*?'. Central to Heidegger's phenomenological approach, which he advanced in *Being and time* (1927) were ontological questions relating to existence. His philosophy explored the possibilities for, and nature of, *Dasein* or 'Being' and how 'Being' *is* in the world (Tietz, 2006; Wrathall & Dreyfus, 2006).

Dasein's fundamental way of being is *in* the world. In the same way that infants, as they develop conscious awareness, find that they are already in a world populated by other people, beings and objects, so Dasein is 'always already' in the world: 'a bare subject without a world never *is*' [emphasis added] (Tietz, 2006, p. 169). In other words, we cannot separate ourselves from the world to examine aspects of that world (Dreyfus, 1978). Dasein's possibilities for being always relate to 'being-in-the-world' and are always relative to other entities. Heidegger described the situated nature of our being in a pre-existing world as being "*thrown* into a world of objects, 'ready to hand', that is, ready to be used" [emphasis in original] (Smith et al., 2009). We implicitly understand the objects that are part of our 'average everydayness' in terms of uses we make of them and their potentialities (Mulhall, 2013, p. 20). This tacit understanding of everyday phenomena comes from the concept of *intersubjectivity* – the fact that 'Dasein is always *Being-with*' [emphasis in original] (Smith et al., 2009, p.17). Our evolved and inherited understanding of the world emanates from a shared existence with other entities – inanimate, animate, and human (Guignon, 2012).

Merleau-Ponty (1962) extended Heidegger's concerns for Being-in-the-world by considering the embodied nature of our existence. He proposed that Being-in-the-the world means we understand the world in three ways: first, in the most basic biological sense of the processes necessary for survival; second, in the way our bodies constrain and enable – or *afford* – the acquisition of motor skills; and third, in the way our body's motor-skill capacity interacts with the socio-cultural environment we inhabit to develop cultural skills. Dreyfus (1996) provides the culturally-specific example of mailing a letter, 'an affordance that comes from experience with mailboxes and the acquisition of letter-mailing skills' (n.p.). Returning to the school gate example, the affordance of using the gate comes from previous physical experience and an understanding of property boundaries and who belongs inside.

Smith and colleagues (2009) describe our complete physical interconnectedness with the world as a 'situated viewpoint [of the world from] which we can never escape' (p. 18). That is, all knowledge is personally interpreted knowledge. The significance of this for IPA, and for a study focused on relationships, is two-fold. First, our ability to view an experience from another's perspective is always related to our own – for the other, 'these situations are lived through', but, for me 'they are displayed' (Merleau-Ponty, 1962, p. 415). The IPA researcher must make an active interpretive effort in order to understand an experience from the participant's perspective. And part of that effort is to examine their own assumptions. Second, if our understanding of the world is shaped by being a 'body-in-the-world', then sensations become defining factors. That is, we understand our experiences through the way in which we perceive them bodily or physically. Catastrophe causes us to *fall to pieces*; we are *crushed* by bad news.

##### 3.2.5.1.1. Connecting Conceptual Metaphor Theory and Interpretive Phenomenological Analysis

Conceptual Metaphor Theory (CMT) (Lakoff & Johnson, 1980/2003, 1999) acknowledges a debt to Merleau-Ponty's efforts to draw attention to our embodied and subjective experience of the world and provides a link between Merleau-Ponty's philosophical concepts and contemporary research in neuroscience. CMT proposes that all meaningful thought, all reasoning, is embodied and emotionally engaged, mostly unconscious and mostly metaphorical. Conceptual structures evolved from the fact that we live in, and move through, the world and that the brain is connected to the environment via the body and bodily experience. Universal conceptual systems are constrained and informed by shared fundamental physical experiences of gravity, physical orientation, hunger, thirst, warmth and cold and so on (Lakoff, 2014). Other experiences are more culturally specific and orientated within particular time periods. Lakoff (2014) advances the idea that, in humans, the sensory-motor circuit that provides sensory information about these experiences has been ‘re-purposed’ for use in the communications structure that governs thought and language in humans. Far from being a mere literary or poetic device, conceptual metaphors are the linguistic expression of specific conceptual structures – primary metaphors represent the sensory-motor experiences that are universal to humans and the link between abstract concepts and concrete experience (Grady, 1997). Complex metaphors combine primary metaphors and generally have a culturally specific basis. For example, the orientational metaphor of HIGH STATUS IS UP [emphasis in original] becomes associated with the complex, and socially meaningful, metaphor of ‘He’s *climbing* the ladder’ [emphasis in original] (Lakoff & Johnson, 1980/2003, p.16). In schools, ‘*high* grades’ are not just associated with numerically higher numbers, but with a student’s ranking in the class. Being in the *top* or *bottom* classes is visibly associated with academic, and often social, status. Lakoff and Johnson (1980/2003) argue that conceptual metaphor is so much a part of the way we think about our everyday lives, structure what we perceive as reality, and communicate our thinking to others, that we are oblivious to the incidence of conceptual metaphors in our day to day language.

Prior to the current study my understanding of metaphor was from a literary perspective. During the first stage of data interpretation, I was alerted to the rich and expressive use of metaphor in each participant’s story. I was also struck by the connection between repeated use of ‘signature’ metaphors and emerging thematic patterns – the participants’ use of metaphor appeared to both articulate and structure the way they thought and felt about an experience. However, when I asked each participant about these metaphors, most were unaware of using any metaphors at all. This structuring of experience through, and apparently unconscious use of, metaphor to explain actions and perceptions provided a way to mediate the participants’ subjective lived experiences and their accounts of those experiences. On further investigation, CMT emerged as a significant interpretive lens through which to explore the participants’ experiences. This is illustrated in Research Journal excerpts (Appendix 9).

#### 3.2.5.2. IPA as a hermeneutic approach to research

IPA accepts that a phenomenological inquiry can never escape our fundamental involvement with the world. Since, for Heidegger, experience is always from a ‘person-in-context’ perspective (Smith et al., 2009, p. 17), that is, we are inseparable from the world, any inquiry into experience must be subjective and interpretive in nature. The processes of interpretation that underpin IPA research relate to hermeneutics, the theory of interpretation, initially of texts, but also of symbols, forms of artistic representation or social actions (Laverty, 2003; Sloan & Bowe, 2014). In IPA studies, experience, and the meaning people attach to that experience is always viewed through a ‘hermeneutic lens’, that is, the researcher’s interpretive lens (Smith et al., 2009, p.18).

More specifically, IPA analysis is based on the idea of the ‘hermeneutic circle’, an analytic cycle that represents the interpretative interdependence of the components within any holistic structure of meaning (Malpas, 2018). This ‘dynamic relationship between the part and the whole’ (Smith et al., 2009, p. 28) is a flexible and iterative process of repeatedly moving from whole-to-part-to-whole; and it takes time and commitment to move ‘from the particular [interpretation at the sentence, theme and text level] to the holistic’ (Smith et al., 2009, p. 104; see also Hefferon & Gil-Rodriguez, 2011; Larkin, Watts & Clifton, 2006). Making sense of the data and clarifying the emerging picture of the participant’s lived experience is analogous to understanding the relevance of a grain of sand in its relationship to the beach as a whole (Wang, 2015).

From Heidegger’s perspective of Dasein ‘always already’ in the world, we are only able to understand a ‘thing’ because of our own situatedness in the world. Relevant to the current study, I understand the concept of parenting, for example, because I have prior experience of my own parents, of other people’s parents, of artistic and scholarly representations of parenting, but most significantly, because of my own parenting experiences. It is this prior knowledge that allows me to understand the concept of parenting, but also which gets in the way of understanding the parenting experiences of others (Smith et al., 2009).

This situated understanding of an experience is determined by our personal viewpoint or, as Gadamer (1990/1960) put it, our personal ‘horizons of understanding' (in Moran, 2000, p.252). Intersubjective understanding, that is, seeing something from another's perspective requires a 'fusion of horizons' (in Moran, 2000, p. 252) which is an iterative process of identifying and revising our *fore-conceptions*, or preconceptions and assumptions, through dialogue. Gadamer thought that we do not become fully aware of fore-conceptions until we encounter an idea (another person's horizon of understanding). If 'unity of meaning' is only achieved through identifying and revising our fore-conceptions, then it is not possible to 'bracket' or set aside subjective assumptions about a phenomenon prior to encountering the participant's perspective (Fleming, Gaidys & Robb, 2003). This concept was strongly illustrated for me, throughout the course of the current study, when every successive encounter with the participants uncovered yet another set of personal assumptions about 'disability', education, and parenting.

Hermeneutic phenomenology, as practised by van Manen (1984, 1990) establishes that the act of interpreting another's experience is a form of mediation between the meaning participants assign to experience, and the phenomenon 'towards which the interpretations point' (van Manen, 1990, p. 26). In the act of uncovering the essence of a phenomenon, the researcher pays close attention to the participant's interpretation but resists the temptation to add their own.

Smith (2007) argues that IPA has more in common with Schleiermacher's (1998) suggestion that the researcher is as concerned with what they understand the participant to *mean*, as with what the participant *says*. An effective analysis of a text (such as an interview transcript) can result in "'an understanding of the utterer better than he understands himself'" (Schleiermacher, 1998, pp.8-9 in Smith, 2007, p. 4). The process of the researcher 'trying to make sense of the words used but … also trying to make sense of the person who has said those words' (Smith, 2007, p. 5) forms the 'double hermeneutic' endeavour that is characteristic of IPA studies. Following Schleiermacher's suggestion, and substantiated by my own research journal, it could be argued that there is an additional interpretive process at work; in which the researcher makes sense of her own experiences, whilst interpreting the participants' narratives. This process is illustrated in Figure 3.1.

In making sense of the participant's own interpretation, the IPA researcher takes a middle ground between a 'hermeneutics of empathy', which avoids imposing any outside interpretation on the phenomenon, and a ‘hermeneutics of suspicion’ which imposes theoretical constructs on the phenomenon (Ricoeur, 1970 in Smith et al., 2009, p.36). Smith et al., (2009) advise that ‘a successful interpretation is one which is principally based on a reading from *within* the terms of the text which the participant has produced’ (p. 37). Even so, IPA studies make explicit links between the interpretive findings and the wider research literature in that field (Smith & Rhodes, 2015).

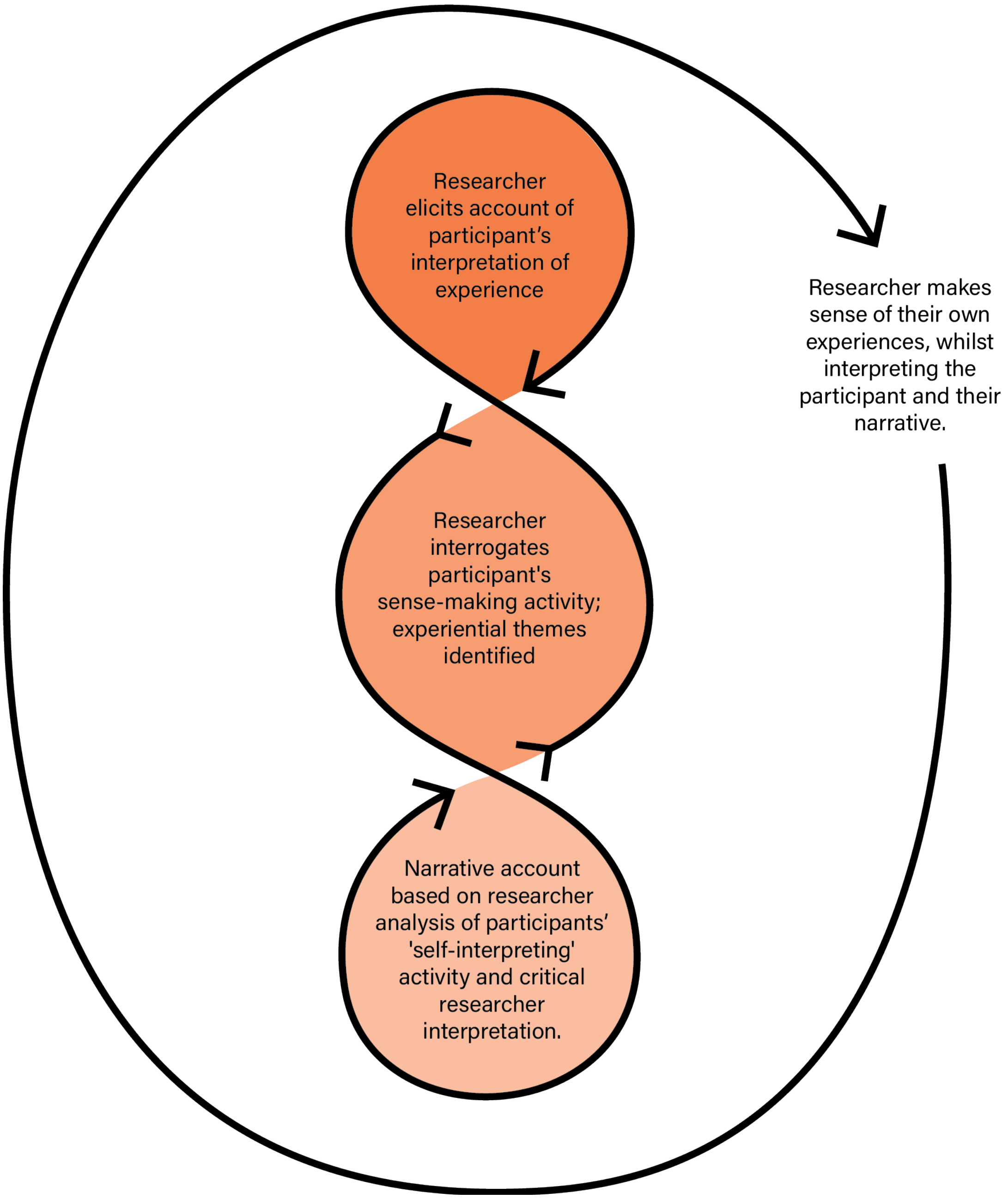


*Figure 3.1* Double Hermeneutic – adapted from Pietkiewicz & Smith (2014); Smith et al., (2009).

#### 3.2.5.3. IPA as an idiographic approach to research

Smith and colleagues (2009) argue that IPA's concern with the particular is manifested in two ways: the concern for detail within the process of interpretation, and the concern for the individual's experience. The process of data analysis proposed by IPA researchers clearly demonstrates a focus on the individual's subjective experience before the researcher (cautiously) draws more general conclusions. These concerns stem from the psychological origins of IPA on the one hand, and from Heideggerian phenomenology on the other.

IPA originated in a concern that psychology could be 'both experimental and experiential' (Smith et al., 2009, p. 4) and as a reaction to the nomothetic claims of experimental psychology, which emphasises group data over individual cases (Smith, 2004). The small number of participants in typical IPA studies prioritises the particular in two ways – it allows for the emphasis on an individual's experience, and for a more detailed level of interpretation of that reported experience. While the analytic process in IPA allows for exploring themes common to participants, it only cautiously moves towards establishing an invariant structure or 'essence' of the investigated phenomenon (Smith, et al., 2009).

IPA's other claim to an idiographic focus derives from Heidegger's concept of Dasein. Dasein, or being, is an individual entity; while we can only understand Dasein's experience in terms of its relationship to the world and others in that world, Smith and colleagues (2009) argue that the individual's observations on their relationship to a phenomenon, is a valuable perspective on that phenomenon.

### 3.2.6. Strengths and limitations of IPA

IPA is an increasingly popular approach to qualitative research but has received some degree of criticism. Some researchers have expressed concerns about IPA's apparent philosophical shortcomings (Giorgi, 2010; Sousa, 2008; van Manen, 2018), while others critique the way in which IPA is applied in practice to research projects (Hefferon & Gil-Rodriguez, 2011; Larkin et al., 2006). This section outlines the strengths and limitations of IPA in relation to this study.

#### 3.2.6.1. Strengths of IPA

Larkin and colleagues (2006) state that IPA ‘remains a ‘young’ approach to qualitative analysis, characterized by open debates and collegiate development’ (p. 105). Apart from the methodological fit between IPA and the current study’s research question, IPA’s flexibility was attractive. IPA has a supportive and dynamic research community that appears to take a pragmatic rather than dogmatic attitude towards phenomenological research and is open to the continued evolution of the methodology (Eatough & Smith, 2017; Smith, et al., 2009).

For those researchers without training in psychology, there may be some concerns regarding a conceptual framework for the analytical / interpretive stage of the research. However, Smith and colleagues (2009) clearly state that this is *p*sychological not just *P*sychological research [emphasis added].

#### 3.2.6.2. Concerns regarding IPA’s theoretical position

There is a persistent argument that IPA could be strengthened if researchers paid greater attention to its philosophical underpinnings. Disentangling the ideas of Husserl and Heidegger can be elusive and this is possibly why the theoretical commitment of some IPA studies has been critiqued (Hefferon & Gil-Rodriguez, 2011; Larkin et al., 2006; Rodham, Fox & Doran, 2015; Shinebourne, 2011). These concerns are addressed by Smith and colleagues (2009) with a (less emphatic) version of van Manen’s (1990) argument that you cannot do phenomenology without a strong understanding of the original philosophies. The novice researcher is cautioned that the ‘underlying philosophy is just as important as matters of procedure’ (p. 5).

In recent articles, Smith (2018, 2019) has re-stated IPA’s position in relation to phenomenological research. He has argued that IPA’s ‘particular focus on the reflective domain’ puts it at odds with van Manen’s focus on the ‘pre-reflective … meaning of experience’ (Smith, 2018, p.1956). In other words, in IPA, both participants and researchers are engaged in making meaning of experience. He has also stated that IPA’s main concern is with experiential meaning and, in particular, the meaning attached to ‘a particular thing, for a particular person, within a particular context, [which] speaks to IPA’s idiographic commitment’ (Smith, 2019, p.169).

Smith may feel the need to reiterate what IPA is and how it is a phenomenological approach because he is engaged in ongoing scholarly discussion with Max van Manen, who is a proponent of hermeneutic phenomenology. Their debate centres on the question of whether IPA is an interpretive phenomenological approach or, as van Manen (2018) contends, a form of 'Interpretive Psychological Analysis' (p.1959). Smith (2018) holds the position that van Manen both misunderstands and 'misrepresents' IPA by suggesting that it is 'a psychological "therapy-oriented" research methodology rather than a phenomenological approach' (p.1955). He also argues for a wider interpretation of phenomenology, taking exception to the idea that 'any one person [i.e. van Manen]… prescribe rules about what does or does not constitute phenomenology' (Smith, 2018, p.1957).

More recently, Dan Zahavi, a philosopher and authority on phenomenology, contends that neither van Manen nor Smith are correct. Zahavi (2019) suggests that, while IPA 'seeks to provide rich experiential descriptions' this might not be enough to 'secure its phenomenological credentials?' (p. 900). He then counters Smith's (2018) argument that researchers 'cannot lay claim to a single, definitive form of phenomenology because phenomenological philosophy is diverse' (p. 1956), stating that by 'labeling itself the way it does … IPA clearly stresses the link between its own endeavor and the phenomenological research tradition' (p. 901). van Manen is charged with 'unwittingly propagating the same superficial and trivialized understanding of phenomenology' (p.901).

I include these aspects of the debate to illustrate that there is no clear consensus on what constitutes phenomenological inquiry or whether IPA meets that description. Zahavi (2019) closes by advising that qualitative researchers 'let their own research be informed by central phenomenological concepts such as lifeworld, intentionality, empathy, pre-reflective experience, horizon, historicity, and the lived body' (p. 905). Arguably, that is what IPA researchers strive to do.

#### 3.2.6.3. Concerns regarding IPA's practical application

Hefferon and Gil-Rodriguez (2011) argue that the proliferation of 'poorly constructed, primarily descriptive projects' reflect a misconception that IPA 'is simply a form of thematic analysis with little emphasis on interpretation and is therefore… the easy option' (p. 756). There are concerns that the principles of positivist research do not apply to IPA yet are still applied in some IPA research projects (Larkin et al., 2006; Shinebourne, 2011). It is argued that large numbers of participants, rigid interview schedules and the inclusion of too many themes contribute to shallow and descriptive studies that lack a commitment to IPA's theoretical underpinnings (Brocki & Wearden, 2006; Hefferon & Gil-Rodriguez, 2011).

There are clear guidelines for conducting an IPA research project (Palmer et al., 2010; Smith et al., 2009) but in their survey of IPA studies, Brocki and Wearden (2006) note that researchers often fail to explain or justify their research methods. Rodham, Fox and Doran (2015) echo this concern and state that authors of some IPA studies 'explain how they conduct [IPA], but fail to explain how they ensured that their analytical process was trustworthy' (p. 59). Although both studies note the constraints of word limits, clearly this is an issue that needs to be considered in conducting IPA studies.

## 3.3. **Research methods**

### 3.3.1. Ethics

This research was approved by The University of Southern Queensland's Human Research Ethics Review Board. Ethics approval was consistent with the University's Research Code of Conduct Policy (2007), the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council [NHMRC], 2007), and the National Statement on Ethical Conduct in Human Research (NHMRC, 2007) (Appendix B). As recruitment progressed, I was granted an amendment to the initial ethics application for the use of alternative participant recruitment methods.

Participants were provided with Invitation to Participate letters that outlined the study and researcher details; Participant Information forms; and Participant Consent forms before volunteering to participate (Appendices C, D and E). All participants reviewed the Participant Information Letter and signed the Consent Form. Participants were invited to review transcripts of their interview and were offered a summary of research results on request. They were given the opportunity to withdraw from the study at any point.

Pseudonyms were assigned to each participant and her child, and significant details (schools, third parties and city names) related to their identification were changed or omitted to limit the possibility of linking particular responses with the research participants. All documents, transcripts, and digital recordings have been kept in a locked and secure location. All electronic files were encrypted, and password protected.

Official ethics guidance procedures cannot anticipate all risk to all participants. Ethical issues also relate to considerations of hierarchy and power between participant and researcher, positioning the participant's voice in the research and the potential problems of engaging in emotional research and with people you know (Allmark et al., 2009; Campbell, 2002; McConnell-Henry, James, Chapman & Francis, 2009). These issues are addressed as aspects of the data collection and data presentation.

### 3.3.2. Research setting

The current study took place in a regional inland Australian city (called 'Regional City' throughout) with a predominantly Anglo Celtic population of over 100,000 (ABS, 2016). The city is the business and administrative centre for surrounding rural towns and primary industries. The city is also an education centre for the region, with both a TAFE Queensland and university campus, and numerous government and Catholic Education primary and high schools. There are several independent schools: large and small, single-sex and co-educational, day and boarding. The participants' children attended a cross-section of Regional City schools.

### 3.3.3. Participants

#### 3.3.3.1. Theoretical issues: Identifying and locating participants in IPA studies

Noy (2008) argues that sampling procedures play an 'undeservedly minor role' in any discussion of qualitative methods but are, in fact, 'crucial moments' within the research design that shape the nature of the participant-researcher relationship (p. 328).

For this study, its ‘crucial moments’ have all centred on the participants. The focus of the proposed and the completed research project were ultimately different, and that difference principally related to the participants – the experiences they related, and the challenges associated with the recruitment process.

Participants in an IPA study are usually selected purposively on the basis that the topic is ‘something that *matters* to the participants … [who] can offer a valuable perspective on the topic at hand [emphasis in original]’ (Larkin &Thompson, 2012, p. 103). The current study employed purposive criterion sampling to recruit participants who had shared similar experiences of, and were most likely to provide meaningful detail about, the research phenomenon (Huberman & Miles, 1994; van Manen, 1984), and whose lived experiences were most likely to illuminate and provide answers to the research questions (Marshall, 1996; Richards & Morse, 2012).

Smith and colleagues (2009) identify three methods of recruiting potential participants: ‘*referral*, from various kinds of gatekeepers; *opportunities*, as a result of one’s own contacts; or *snowballing* (which amounts to referral by participants) [emphasis in original]’ (pp. 48-49). In this study, difficulties with participant recruitment resulted in the use of all three.

#### 3.3.3.2. Practical issues: Gaining access to participants

##### Phase 1: Recruiting participants via referral from primary schools

The study initially focused on a very narrowly homogenous, criterion-based group of participants (Huberman & Miles, 1994): parents whose children were within a specific age range, transitioning to high school within a specific time frame and who had been identified in the primary setting as having anxiety related to learning, social or behavioural difficulties.

Three primary schools within the target area were selected on the basis of their reputation for inclusive practices and active parent communities. Each school Principal agreed to pass on the research details to potential participants, whose child had completed Year 6 or 7 at the primary school. Parents were then to express their interest by making direct contact with the researcher; ethical constraints meant I could not contact parents directly.

Unfortunately, I encountered great difficulty in locating and interviewing potential participants via this strategy. Although three parents (one from each of the three target primary schools) originally expressed interest in the study, only one followed up on the initial contact. After a few months the schools each agreed to place a flyer, inviting parents to participate, in their newsletters (Appendix F). On the face of it this was also unsuccessful, but word spread.

Difficulties in recruiting participants via school-issued invitations may be attributed to:

- **Issues of trust. School staff:** The school leaders and Learning Support staff acted as 'gatekeepers' for the initial round of recruitment (Curtis, Gesler, Smith & Washburn, 2000; Groger, Mayberry, & Straker, 1999; Waters, 2015). These staff members decided which parents would be most suited to participating in the study and, although they most certainly acted in good faith, this process may have distorted the selection process. While other parents from the same school as the sole respondent parent, meeting the same criteria, ended up participating in the study, school staff had not invited them to participate (Researcher Journal, 2015).

- **Issues of trust. Parents:** Parenting a neurodiverse child with anxiety carries some stigma and sets these parents apart from the parents of typically developing children. Potential participants may have found it difficult to trust a stranger who wanted to discuss and make public very personal issues, regardless of the condition of anonymity. The flyers in the newsletters requested that parents collect study details from the school office, but parents later made it clear to me that they were reluctant to let anyone at the school know they were participating in the study (Researcher Journal, 2015). I was also told by parents, who had younger children at the primary school, that they were worried negative consequences might be attached to their participation (Waters, 2015).

- **Issues of power:** Differing perceptions between parents and educators about children's needs can be a significant source of conflict between parents and educators (Lake & Billingsley, 2000). This conflict is an expression of the power relations between educational professional and parent and often extends to the 'power relations which transpire between researcher(s) and researched' (Noy, 2008, p. 329). Potential participants may have been unwilling to trust, or make time for, a researcher who had identified themselves (in the introductory letter) as a teacher.

### Phase 2: Recruiting participants via flyers in psychologists' reception areas

In Phase 2 I advertised the research project via flyers in the reception areas of educational psychologists' offices but attracted only one further participant to the study (Parent B) (Appendix F). Of the eight psychologist's offices that were contacted, only two agreed to display the flyers. Furthermore, this required an alteration to the Ethics Application which extended the data collection period (Appendix G). Difficulties relating to this strategy may have been due to 'gatekeeper bias' which is demonstrated among those who have responsibility for and are protective towards those in their care (Atkinson & Flint, 2001).

### Phase 3: Recruiting participants via opportunities and Snowball Sampling

During the first two years of the current study, I informally discussed my research project at parenting seminars and parenting group meetings and let parents know I needed participants (Waters, 2015). Ultimately, the remaining participants were introduced to me by the first respondent, via word of mouth (Parent A) and through referral from subsequent respondents. This process is illustrated below.

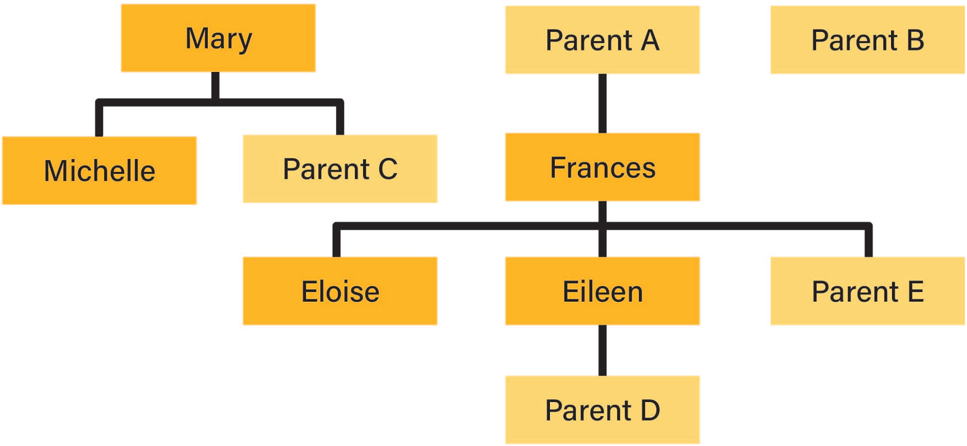


*Figure 3.2* Chain of referral

This method of chain referral is generally known as Snowball Sampling – a purposive, yet not always pre-determined, sampling method that helps access hard to reach or ‘hidden’ participant populations (van Meter, 1990) such as the economically and socially disadvantaged, and the ‘socially stigmatised’ (Atkinson & Flint, 2001). In relation to the study context, the latter could describe the participants and explain their wariness.

Snowball Sampling is not always pre-determined because it is usually employed as an auxiliary means of augmenting the participant sample when other means are unsuccessful. While it is commonly used (Noy, 2008), there are inherent methodological and practical challenges for Snowball Sampling (Waters, 2015) that relegate it to ‘the margins of research practice’ (Atkinson &Flint, 2001, p. 1).

Most methodological issues with Snowball Sampling relate to statistical accuracy, generalisability and bias towards those participants who are known to the initial referees, resulting in sample groups with “relatively homogenous social traits” (Atkinson & Flint, 2001). Table 3.1 demonstrates this homogeneity – because the participants came from similar social backgrounds and were sometimes part of the same social network, they shared similar characteristics (Waters, 2015). While this needs to be accounted for, it is not the ‘distortion’ it would be in a quantitative study.

The main practical disincentive for using Snowball Sampling is that it is both time consuming and labour intensive (Atkinson & Flint, 2001; Waters, 2015). In the current study, the process of finding an adequate number of participants whose experiences were appropriate to the research questions took the better part of two years.

Snowball Sampling also highlights issues of researcher: researched control (Noy, 2008). Respondents make the decisions about who to invite or exclude and the researcher really only has the power of veto. I found this to be problematic as several potential participants, referred by other respondents turned out to not meet the research criteria (Parents C, D and E). I risked offending the referrer and marginalising the potential participant if I did not include their story. Explaining these reasons to participant and referrer was emotionally difficult from all sides.

Nevertheless, rather than being seen as a strategy of ‘last resort’, for three reasons Snowball Sampling was arguably the most suitable strategy for the current study:

- **Breadth:** Parents of neurodiverse children with anxiety talk to each other but may be mistrustful of educational professionals (Shelden et al., 2010). The referring parents went outside their child’s school’s ‘protectorate’ (Pushor, 2012) in recruiting other parent participants. They accessed their wider circle of friends, discussed the study with them and acted as intermediaries between me and the new participants. While this meant for some homogeneity (in terms of gender, SES), the study still accessed a broader demographic than the original school sample would have provided.

- **Trust:** Referring participants organised preliminary, and social, meetings so I could get to know their friends, and, more importantly, so they could decide whether to entrust me with their stories. An important factor in the success of this sampling strategy was that the original participants’ trust in me transferred to the new participants (Waters, 2015). Initial meetings aimed to consolidate trust (Noy, 2008) and establish individual and shared understandings of parenting an anxious child. These understandings provided a framework for the subsequent interview(s).

- **Referral:** One of the issues with Snowball Sampling lies in the difficulty of locating initial respondents or referees to provide ‘a route into the required population’ (Atkinson & Flint, 2001). Two of the initial respondents provided this route and vouched for the authenticity of my research purpose. Thanks to their referral I went from being an ‘outsider’ as a teacher researching parent subjects, to an ‘insider’ discussing shared concerns with fellow parents (Atkinson & Flint, 2001). This presented issues from the perspective of ‘bracketing’ my subjectivities during the research process but enabled the gathering of rich and naturalistic data.

- **Networks:** This strategy tapped into the importance of ‘natural social networks’ to this group of participants and also to the dynamic, dialogic nature of knowledge represented by these relationships (Denzin & Lincoln, 2011; Noy, 2008). I could only access participants’ experiences because they had already discussed the research purpose, question and researcher with their referrer.

In terms of the study's feasibility (Huberman & Miles, 1994), it is clear that the participant recruitment practices had serious impacts: reworking the recruitment strategies caused delays which eventuated in revisions of the research purpose and questions and the type of cases I eventually selected (Curtis et al., 2000). However, it eventuated in a far richer understanding of parent experiences. It also set the stage for the participants to become partners in the research, rather than subjects of the research. Parents contacted me for a purpose, and while the story they told and the message they wanted me to convey was not exactly what I had anticipated, it was *their* experience of the broader research phenomenon.

#### 3.3.3.3. Introducing the participants

There are no definitive answers as to correct sample size in an IPA study (Smith & Osborn, 2003). The researcher is aiming for rich description, from a small and homogenous participant group rather than a large and representative sample; that is, 'quality not quantity' (Smith et al., 2009, p. 51). Recruitment of small numbers of participants is consistent with the practical analytic demands and the inductive logic of qualitative research designs and phenomenological studies in general (Creswell, 1998; Yardley, 2000) and the idiographic focus of IPA studies more specifically (Smith et al., 2009; Smith & Osborn, 2003).

In their survey of IPA studies, Brocki & Wearden (2006) found participant numbers varied from 1 to 30. In the current study, the stories of five participants, from an initial pool of ten respondents, were included because their narratives richly illustrated the central phenomenon. Table 3.1 provides an outline of participant details; Chapter 4 presents each participant's story in depth.

*Table 3.1* Participant information

| **Parent** | **Participant location at time of interview** | **Interview dates** | **Context** | **Child's Anxiety Linked to:** | **Contact** | **Interview setting** |
|---|---|---|---|---|---|---|
| Mary<br>M, 5 children, works part-time | Regional City | 2015<br>2015<br>2016<br>2017<br>Reviewed transcripts | Son, Henry (13) attends urban Catholic high school. Commenced Year 7 2015 | ADHD & Asperger's diagnosis, behavioural difficulties, literacy issues | Personal friend<br>Invited to participate via Catholic primary school | Researcher's home<br>Participant's home |
| Michelle<br>M, 3 children, works part-time | Regional City | 2015<br>2017<br>Reviewed transcripts | Daughter, Cate (19) completed school 2015.Urban Catholic girls' school | Asperger's diagnosis, social difficulties, literacy issues | Prior acquaintance<br>Informed of study by Mary | Researcher's home<br>Cafe |
| Frances<br>M, 3 children, works part-time | Family from rural property. Lives Regional City | 2106<br>2017(with Parent A)<br>Reviewed transcripts | Son, Forbes (MM) (14) attends small suburban Christian school. Commenced Year 7 2013 | Specific Learning Disability (Dyslexia) | Introduced by Parent A<br>Also introduced Parent D | Participant's home<br>Cafe |
| Eileen<br>M, 7 children, works from home | Regional City | 2106<br>2017(with another parent)<br>Reviewed transcripts | Daughter, Emily (15) attends urban Catholic girls' school. Commenced Year 7 2013 | Non-Verbal Learning Disorder | Introduced by Frances<br>Also introduced Parent C | Participant's home<br>Cafe |
| Eloise<br>M, 3 children, works from home | Family from remote, rural property. Lives Regional City | 2016<br>Declined to review transcripts | Son, Rory (14) attends large urban boy's boarding school Commenced Year 7 2014 | Specific Learning Disability (Dyslexia) | Introduced by Frances | Cafe |

## 3.3.4. Data generation

### 3.3.4.1. Accessing participants' lived experience

The current study accessed the participants' subjective lived experience via semi-structured interviews. The process of data collection – from initial meetings with the participants, to successive rounds of interviews, to transcription and, finally, to member checking – is illustrated in Figure 3.3.

While interviews form the principal data collection method in phenomenological and IPA inquiries (Smith et al., 2009), they are not unproblematic (Gubrium, Holstein, Marvasti & McKinney, 2012; Rapley, 2001). Conducting interviews raises practical issues of the 'how and where' – the technical aspects of the interview and the interview setting; and epistemological, ontological and ethical issues of the 'who and what' – the relationship between interviewer and interviewee and the type of knowledge produced (Mann, 2016).

### 3.3.4.2. The how and where

Overly restrictive interview schedules have the tendency to invite reports of, not stories about, participant experiences (Chase, 2003). While the interviews had clear thematic goals (Polkinghorne, 2005), I used the interview schedule, developed from the literature review, flexibly and sparingly (Appendix H). Interviews veered towards the conversational (van Manen, 1990): questions allowed the participants to elaborate on the themes they thought were most relevant to their lived experience and permitted flexibility in the direction of our dialogue (Eatough & Smith, 2017; Palmer et al., 2010; Smith & Osborn, 2008; Smith & Rhodes, 2015). As indicated in Chapter 1, this flexibility, and the process of reflecting on our conversations, led to an adjustment of the research focus (see Figure 3.3)

Each interview began with an open-ended question that allowed the participant to discuss their perception of their child's experience at school: 'Could you please tell me about your daughter/son and what school is like for her/him?' Subsequent questions were a balance of topic-initiating – focused on exploring the participant's beliefs and values relating to education, their perception of the school's inclusion and support practices and their own parental role in their child's education; and follow-up – related to the content or meaning of the parent's narrative (Rapley, 2001). This supported IPA's focus on the collaborative construction of meaning (Larkin et al., 2006; Yanchar, 2015) and helped to substantiate the interpretive process.

The interview setting, and location were negotiated. Being conscious of the potential for power imbalance, I wanted to acknowledge the participants' roles as 'givers' in the interview process (Herzog, 2013). Some chose public spaces such as cafes, which although neutral, possibly hindered open exchange; the participants who chose to meet in public spaces were more guarded and less confiding. Others invited me into their homes which, while shifting the balance of power in favour of the participant, left them potentially more vulnerable to scrutiny of their private family life (Manderson, Bennett & Andajani-Sutjahjo, 2006).

All interviews were audio-recorded with an iPhone recording application, *Voice Recorder and Audio Editor*. This had a number of advantages: it was unobtrusive when interviews took place in public spaces – participants commented that they felt more comfortable than with a traditional recorder – and interview recordings could be sent directly to the researcher's computer and transcription software using a USB cable.

#### 3.3.4.3. The who and what

The 'who' in the interview process refers to the 'active subject' behind the participant whose narrative conceals or reveals the phenomenon depending on their rapport with, and the self they wish to present to, the researcher (Rapley, 2001; Yanchar, 2015). The 'who' also refers to the 'active subject' behind the interviewer whose biography, research purpose, questions, prompts and interpretations invite the participant to tell a particular story (Etherington, 2007). And the 'who' includes the reader who adds their own interpretation.

It is the interaction between the 'who', in the moment and situation of the interview and the reading, that co-constructs the 'what'; that is the substantive content of the interview narrative (Holstein & Gubrium, 2011; Mann, 2016; Rapley, 2001). Given that interview data are generated by situated and contextualised social interaction, individual and interpersonal factors affect the interview process that can (and did) create ethical dilemmas in the current study (Manderson et al., 2006).

#### 3.3.4.4. Positioning of researcher to participant

IPA research values the participant as the ‘experiential expert’ (Smith & Osborn, 2003), positioning the participant as a ‘story-teller not a respondent’ and the researcher as ‘an enabler’ who helps to tease out their story (Eatough & Smith, 2017, p. 30). While this was in keeping with my own personal philosophy, enabling and encouraging the telling of personal stories depends on the rapport between researcher and participant.

#### 3.3.4.5. Rapport between researcher and participant and over-disclosure

Manderson and colleagues (2006) note the significance of age, gender and class in developing rapport and strengthening the interview data. While our shared similarities accelerated my rapport with the participants, this led to its own set of ethical issues (McConnell-Henry et al., 2009). As the participants shared stories of their children’s social, behavioural and learning issues and attendant anxieties, most made it clear that these were not topics they discussed in their general conversation. I was concerned that the increased level of trust might have caused some participants to divulge more than they were comfortable with (Sinding & Aronson, 2003). These were highly emotive subjects for the participants; I had great difficulty in not sharing in the participants’ distress and I found it difficult to judge when to close down a conversational thread that was so obviously distressing and highly personal, but that also brought the participant’s lived experience to life.

There are particular concerns with ‘dyadic inquiry’, where participants discuss a third party, such as their child. This raises issues about the child’s privacy and confidentiality and creates a moral dilemma for researchers – what to do with the stories that illuminate the phenomenon, but which also reveal the child’s vulnerabilities (Allmark et al., 2009). Taking great care with the participants’ stories became an abiding concern and determined the inclusion of participant narratives in Chapter 4.

Researchers too might reveal more of themselves in order to ‘reduce the power differential’ with participants with whom they have developed a friendly relationship (McConnell-Henry et al., 2009, p. 4). I based some of my own self-disclosure on an expectation that the participants’ experiences would be similar to my own (Saukko, 2000). These issues are further complicated when engaging in emotional research and in research with people you know, such as in my pre-existing relationship with some participants, and evolving relationship with others (Campbell, 2002; Dickson-Swift et al., 2009; McConnell-Henry et al., 2009).

#### 3.3.4.6. Pre-existing knowledge

Having pre-existing knowledge about a participant's circumstances can be the source of further dilemmas for the researcher as the participant has consented to 'the use of information only obtained during this particular interview' (McConnell-Henry et al., 2009, p.6). I tended to use any pre-existing knowledge (gained from children attending same school) as a question prompt and tried to avoid using prior knowledge as insights in data analysis.

#### 3.3.4.7. Role conflict

Asselin (2003) believes that role conflict occurs 'when the researcher perceives or responds to events from a perspective other than researcher' (p. 102**).** As a researcher and parent there are elements of empathy and fellow-feeling; but also, a tendency to compare circumstances. It was necessary to consciously reflect on my research purpose, throughout the interview, and resist the urge to think that I knew how the other felt.

### 3.3.5. Researcher reflexivity

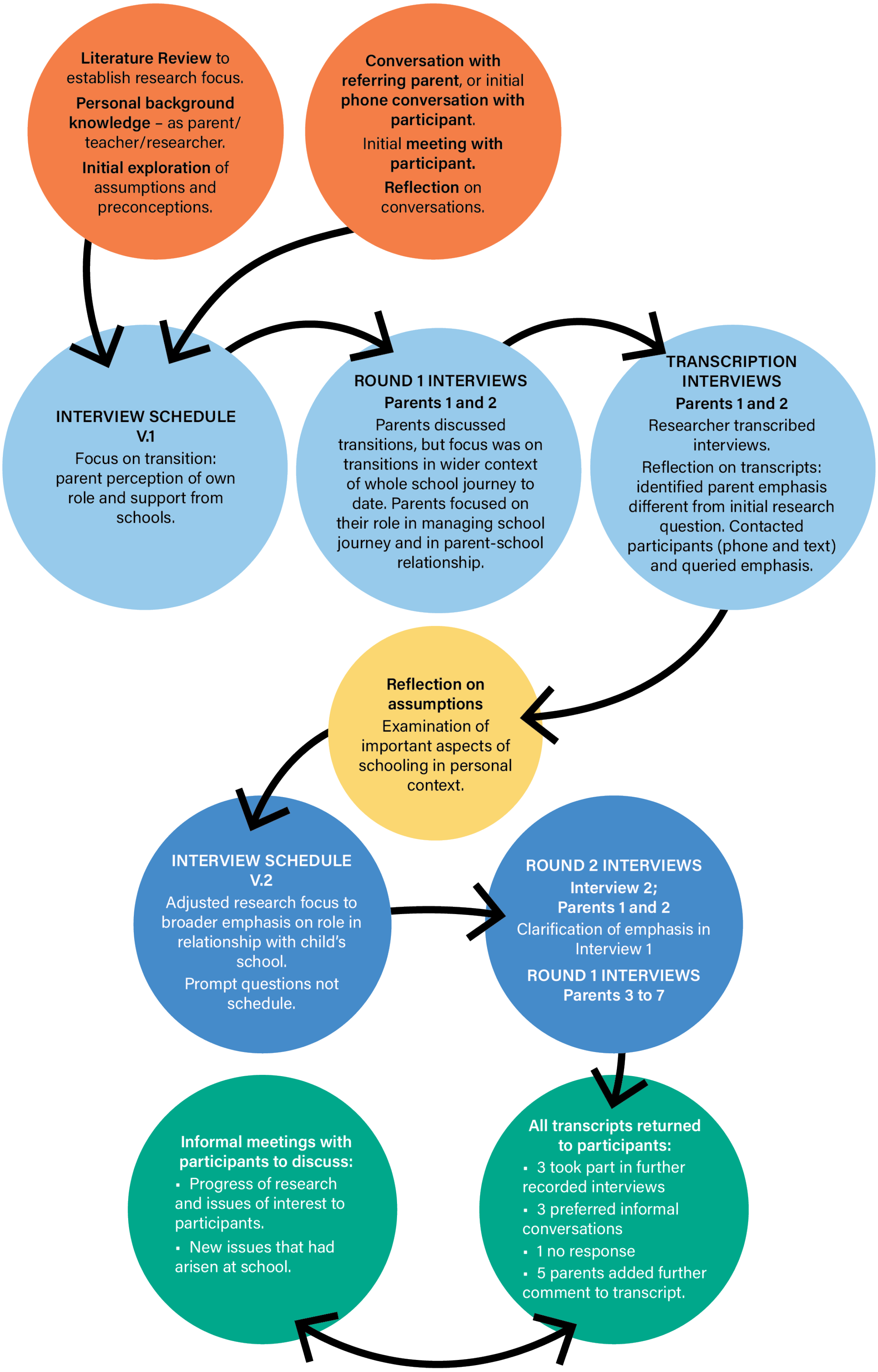
Respecting the participant's trust and minimising potential harm must be the overarching premise of any interview strategy, and points to the importance of researcher reflexivity. Mann (2016) defines this as 'a conscious process of thought and articulation centred on the dynamics of subjectivities in relation to the interviewer, the interviewee(s), and the research focus and methodology' (p. 15).

Declaring the researcher's theoretical assumptions is an important aspect of qualitative interviews in general (Finlay, 2002; Roulston, 2010) and is of particular importance in any phenomenological research; examining and putting aside our taken-for-granted attitudes towards an experience allows for a fresh perspective (Finlay, 2014; Smith et al., 2009). 'Bracketing' takes on different meanings in different research perspectives (Tufford & Newman, 2010) but in IPA it becomes an openness to the phenomenon and sensitivity to the other (Finlay, 2014).

This is not simply a one-off process – we cannot take off our assumptions and fold them neatly away, as our fore-structures re-emerge with each encounter with the phenomenon and each interpretation (Gadamer 1990/1960 in Smith et al., 2009). Consequently, reflection (see Figure 3.3) and journaling became a central aspect of the current study (See examples Appendix I).

### 3.3.6. Phases of data generation

Data collection occurred over a period of two years but did not follow a typical pattern for each participant (see Table 3.1). This was partly related to the participant recruitment process, and partly related to the individual needs of the participants; each needed a different time frame in which to tell their story. One participant had a well-considered story that she told in the space of a single two-hour interview; other participants stayed in contact over the space of the research period. Some told me they were trying to place their experiences in some context; others wanted to demonstrate the recurring nature of their experiences.



**Literature Review** to establish research focus.

**Personal background knowledge** – as parent/ teacher/researcher.

**Initial exploration** of assumptions and preconceptions.

**Conversation with referring parent**, or initial **phone conversation with participant**.

Initial **meeting with participant.**

**Reflection** on conversations.

**INTERVIEW SCHEDULE V.1**

Focus on transition: parent perception of own role and support from schools.

**ROUND 1 INTERVIEWS**

**Parents 1 and 2**

Parents discussed transitions, but focus was on transitions in wider context of whole school journey to date. Parents focused on their role in managing school journey and in parent-school relationship.

**TRANSCRIPTION INTERVIEWS**

**Parents 1 and 2**

Researcher transcribed interviews.

Reflection on transcripts: identified parent emphasis different from initial research question. Contacted participants (phone and text) and queried emphasis.

**Reflection on assumptions**

Examination of important aspects of schooling in personal context.

**INTERVIEW SCHEDULE V.2**

Adjusted research focus to broader emphasis on role in relationship with child's school.

Prompt questions not schedule.

**ROUND 2 INTERVIEWS**

**Interview 2;**

**Parents 1 and 2**

Clarification of emphasis in Interview 1

**ROUND 1 INTERVIEWS**

**Parents 3 to 7**

**All transcripts returned to participants:**

- 3 took part in further recorded interviews
- 3 preferred informal conversations
- 1 no response
- 5 parents added further comment to transcript.

**Informal meetings with participants to discuss:**

- Progress of research and issues of interest to participants.
- New issues that had arisen at school.

*Figure 3.3* Data generation

### 3.3.7. Transcription of data

Each interview was transcribed verbatim by the researcher using Express Scribe Transcription Software Pro v.6.00.

Transcription is an interpretive act, so the data preserved represents the conscious selections and unconscious biases of the researcher (Davidson, 2009; Lapadat, 2000; Mero-Jaffe, 2011). In other words, the record is only complete in terms of what the researcher decides to include and omit. For this reason, participant validation of the transcripts was an important aspect of the data generation process in the current study. While member checking contributes to research integrity, it also ensures the participant's voice is accurately represented in the transcript (Davidson, 2009; Mero-Jaffe, 2011).

#### 3.3.7.1. Participant validation of transcripts

As illustrated in Figure 3.4, each transcript was a composite artefact made up of a range of data sources including interviews, email and text conversations; additional written comments; and researcher questions relating to aspects of the interview. The latter prompted either a hoped-for follow-up discussion (Lapadat, 2000) or a written response from the participant; and sometimes more than one conversation. In effect, each 'composite transcript' was made up of the stories each participant told, over time, about their experiences. However, I was still faced with the problem of presenting these combined stories, for validation, to the participants in some sort of coherent form. I constructed first person narratives through a process of merging the data streams: adding additional material into the original transcript according to the original chronological or thematic order. Reviewing transcripts can be uncomfortable for participants (Mero-Jaffe, 2011) but I hoped that these narratives were closer to the stories that emerged in the interviews.

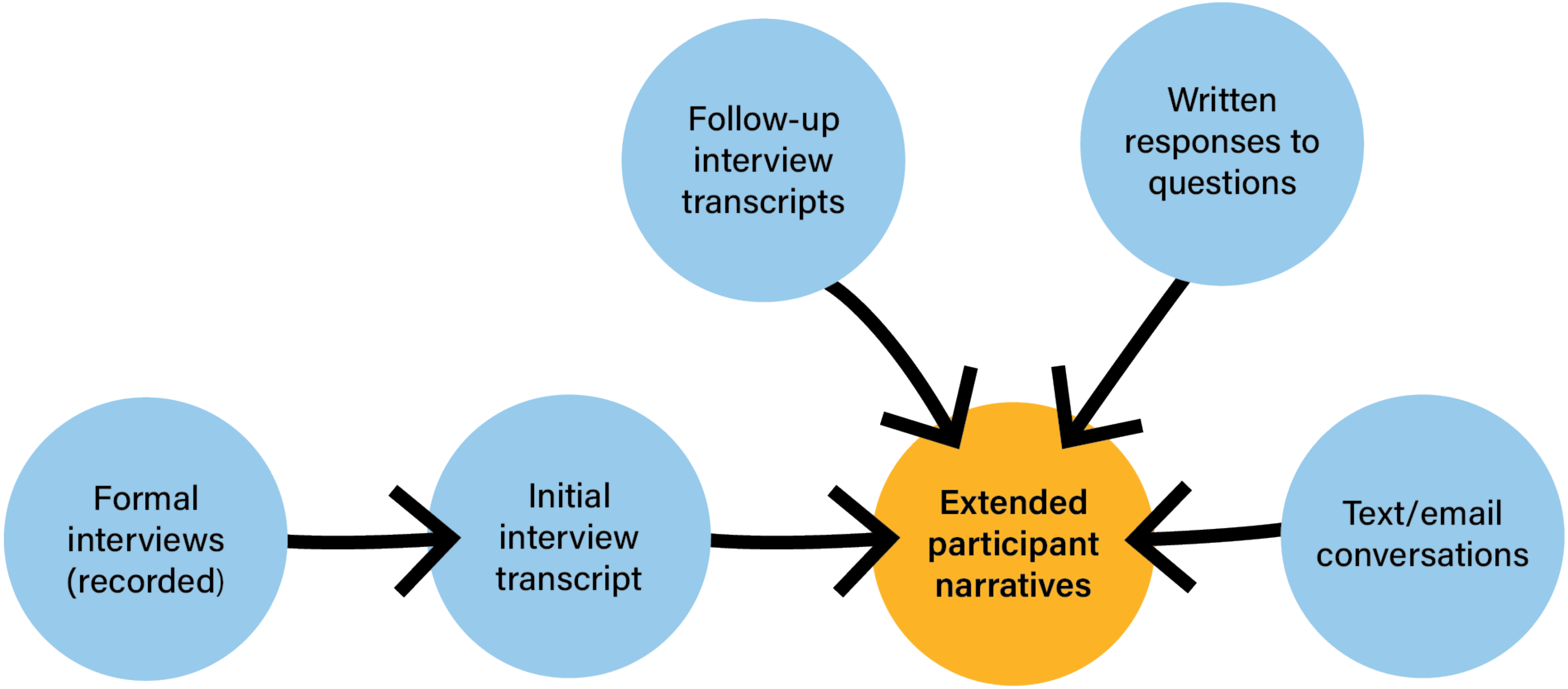


*Figure 3.4* Data set

All but one participant reviewed their extended narratives, the others agreed to further meetings or provided additional written comments. I repeated the process for those participants and offered a second round of narrative validation. Only one participant wanted to review their second, and edited, narrative. This highlights the fact that, whilst researchers might aim for accuracy, representation and shared ‘horizons’, there must be a balance in terms of time and commitment for both participant and researcher (Smith et al., 2009).

### 3.3.8. Data presentation – participant narratives

Werz, Nosek, McNeish & Marlow (2011) identify the tension in phenomenological writing in presenting the findings of qualitative inquiry in a way that conveys the meaning of the experience and that resonates with readers. IPA studies tend to present findings as researcher interpretation illustrated with verbatim extracts from the transcripts (Brocki & Wearden, 2006; Smith et al., 2009). This approach is suited to journal articles; however, the PhD dissertation lends itself to exploring alternative ways to represent participant narratives that are consistent with interpretive phenomenology and an idiographic commitment.

As the participants had established a clear position as co-researchers in the research (Elliot, 2005; Mishler, 1986; Polyani, 1985), in presenting their narratives I sought a compromise between the whole story that emerged in the interview setting, and the atomising tendencies of the interpretive process (Schratz, 1993). Consequently, the participants’ extended narratives were abridged for inclusion in Chapter 4 as a way of contextualising the interpretive and thematised accounts that follow in Chapters 5 and 6. These extended ‘grounding in examples’ (Elliot, Fischer & Rennie, 1999) represent something of the texture and holistic sense of the participant’s lived experience (Werz et al., 2011) and ‘allow the reader to make his or her own assessment of the interpretations made’ (Brocki & Wearden, 2006, p. 222).

It was of key importance that the authenticity of the participant’s voice was retained while allowing for word limitations; editorial elision is routine when including extended ‘grounding in’ examples (Smith, 1999) but this involved a process of condensing the entire narrative, through which the essence of the participant’s experience was revealed. Examples comparing excerpts from Eileen’s unabridged transcript, extended narrative and abridged narrative are included in Appendices J, K and L.

### 3.3.9. Data interpretation

Data analysis methods in IPA are not prescriptive (Palmer et al., 2010), but are based on an iterative process of interpretive engagement with the participant's transcript and involve an inductive process of building theory to explain the picture that emerges (Smith et al., 2009). Analysis of participant transcripts initially proceeds case by case, reflecting the idiographic commitment of IPA. It then moves to examining convergence and divergence between cases, making 'cautious' links to theory and existing research at this point (Smith et al., 2009).

This section outlines the study's process of data analysis and interpretation based on the phenomenological process (Finlay, 2014; van Manen,1984) and procedures relevant to IPA (Palmer et al., 2010; Finlay, 2014; Smith et al., 1999; Smith et al., 2009;).

#### 3.3.9.1. Engaging with theory

The starting point for any IPA research project is an interest in exploring a specific phenomenon, not an interest in testing a particular theory or hypothesis. In IPA studies, theory-driven questions should be secondary to the primary questions, which are 'exploratory not explanatory' and aimed at developing an interpretive phenomenological account of lived experience (Smith et al., 2009, p. 47).

Secondary, theory-driven questions often emerge at the interpretive stage of the research process as a way of making sense of the data. As Smith et al. (2009) explain, these questions 'may engage with a theory but they do not *test* it' (p. 48).

The starting point for the current study was the phenomena of neurodiverse students' schooling experiences and parent-school interactions. I was interested in how the participants' perceived their child's experience. I was interested in what constituted an effective relationship or partnership, from the parents' perspective, and whether they felt their child's anxiety and neurodiversity affected this relationship. I was also interested in how parents viewed their role in this relationship and in understanding their motivations for being involved in their child's education. Thus, the current study was designed to illuminate these participant experiences and perceptions, not to test a particular hypothesis or theory.

That said, as an educator, I am familiar with numerous theories of learning, instruction and child development, including Bronfenbrenner's Ecological Systems Theory (1977, 1986, 1992) and Bioecological Systems Theory (Bronfenbrenner, 2001; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 1994). These developmental theories were introduced in Chapter 2 as an organisational framework for the literature discussion but also presented as a way of engaging with both the research questions and issues raised by the interview data. The child's interactions within their immediate home and school environments, and their parents' interactions with the school community are central to the parent-school relationship.

EST is also congruent with the research methodology. IPA emphasises that experience is always understood from the perspective of the person in context, and EST places the same emphasis on the situated and related nature of experience: we are inseparable from our environment. Throughout successive iterations of his theories, Bronfenbrenner emphasises that the ecological model considers both the 'objective properties' of a given environment and the 'way in which these properties are *subjectively experienced* by the persons living in that environment' [emphasis added] (Bronfenbrenner, 2001a, p.5).

Tudge and colleagues (2016) contend that ESTs are frequently 'misused' in the research literature and stress that an appropriate use of the models requires a focus on person-process-context-time. The authors reiterate Bronfenbrenner's own emphasis and suggest that hypotheses cannot be accurately tested without considering how the individual's characteristics interact with two or more settings and within a longitudinal context. While the current study did not aim to test theory, the themes raised by the interview data, which cover significant periods of the child's schooling, were viewed through two aspects of EST: the interaction between the developing child's individual characteristics and their microsystems; and parent-school interactions. That is, within, and between systems relationships.

### 3.3.10. Stages of data interpretation

#### 3.3.10.1. Immersion in the participant's lifeworld – Looking at the whole

The initial stage of becoming familiar with the data (Braun & Clarke, 2006) was a process of 'entering the participant's world' (Smith et al., 2009, p. 82) through an extended period of dwelling with the interview recordings and transcripts, data streams and extended narratives (Finlay, 2014). As van Manen (1984) explains, this is the process of "turning 'to the things themselves"' (p. 3) and developing a holistic sense of the phenomenon.

My personal 'filters', or interpretive lenses through which I attended to the data (Abawi, 2012) were identified through an examination of personal preconceptions (c.f. Smith, 2007). These were explored in my Research Journal both prior to and during data analysis and based on my personal experiences as a parent, teacher and researcher. These were outlined in Chapter 1.

#### 3.3.10.2. Initial comments – an intense focus on significance and the 'part'

During the second stage of analysis, a detailed line-by-line examination of the participant's experiential claims involved noting anything of interest or significance within the text of the interview transcripts and additional data streams (Smith, Jarman, & Osborn,1999; Smith et al., 2009). An example of the initial notation phase is included in Appendix M. Comments were descriptive and focused on the content of the participant's narrative. Comments were also linguistic and focused on the participant's use of metaphor. IPA focuses on what analysis of discourse can tell the researcher about the experience, but not on the way in which the language shapes that experience (Smith et al., 2009). Lakoff and Johnson (1980/2003; 1999) argue that the crucial point to conceptual metaphors is not the language but its ability to link language and concept, that is, the ideas and assumptions they represent. As the use of CMT in data analysis is an established methodology in qualitative research (Abawi & Conway, 2013; Creed & McIlveen, 2018, Schmitt, 2005), this emerged as a secondary theoretical framework to guide data interpretation.

Lakoff and Johnson (1980/2003) identify three overlapping categories of conceptual metaphors: Structural, Orientational and Ontological Metaphors.

- *Structural Metaphors* structure the way we think about an everyday activity, such as education, in terms of another. LEARNING IS A JOURNEY is an example of such a metaphorical concept. Metaphoric mapping takes our existing knowledge or reasoning about journeys and systematically 'maps' or applies it to a different situation: the journey metaphor, its vehicles, travellers and impediments, is commonly extended to education (Sfard, 2014). Students are travellers on a journey and journeys have destinations – governments, educators, parents and students (hopefully) have common educational goals and the schooling journey's end is symbolised by the Year 12 graduation. The process of schooling is a vehicle that can travel on a road or tracks or stall or even break down if there are difficulties or impediments to moving forward on the journey.

- *Orientational Metaphors* organise 'a whole system of concepts with respect to another' (Lakoff & Johnson, 1980/2003) and have a physiological origin in neural systems that orientate the body in space and in relation to objects. These metaphors give concepts such as success a spatial orientation – SUCCESSFUL IS UP. These experiential metaphors also generate metaphoric systems with cultural coherence such as HIGH STATUS IS UP/ LOW STATUS IS DOWN.

- *Ontological Metaphors* project concrete concepts onto abstract concepts (Lakoff & Johnson, 1980/2003). The conceptual metaphor – MIND IS MACHINE – reflects common reasoning about the computational function of the mind in learning. When knowledge becomes an entity it can be constructed, added, stored, retrieved or lost and, Sfard (2014) argues, learners can become objectified along with knowledge.

Examples of these conceptual metaphors were identified on a case-by-case basis during the transcript analysis (see excerpt Appendix N) and noted for frequency and significance. Conceptual metaphors and metaphorical expressions were then grouped across participants in specific themes and sub-themes and according to the abstract concepts that they articulated. This is illustrated in Appendices O and P.

The representation of conceptual metaphors and metaphorical expressions in this thesis follows the examples established by Lakoff and Johnson (1980/2003). Conceptual metaphors and organising frames and schemas are indicated in small capitals. Metaphorical expressions that provide everyday examples of conceptual metaphors are indicated in italics.

Recently, arguments have been developed for the unity (and utility) of Conceptual Metaphor and other non-verbal and multimodal forms of communication (Coëgnarts & Kravanja, 2012; Forceville, 2009; Peterson, Wise, Lindgren, Cox & Mathayas, 2015). Each of the Conceptual Metaphors used by the participants to communicate experience has a visual quality, a capacity related to a complex function of working memory (Peterson et al., 2015). While research exploring the link between conceptual and visual metaphors is in its early stages (Feng & O'Halloran, 2013; Peterson, 2018), a decision was made to use visual metaphors in Chapter 6 to reinforce the participants' use of conceptual metaphors. As these visual metaphors were chosen by the author rather than the participants, their inclusion invites a co-construction of meaning and encourages insight into the participants' shared experiences of parenting phenomena.

#### 3.3.10.3. Emergent themes

During the third stage of analysis, the data was examined for salient examples of content and conceptual metaphor and what Smith (2011) calls 'the gem' – the description, phrase or metaphor that stands out and offers 'analytic leverage [and] shine[s] light on the phenomenon' (p.7). These emergent themes captured the essence of the participant's account and were clustered, in separate tables for each participant.

Phenomenologists describe the process of uncovering themes and 'doing' phenomenology as 'creative' (Smith et al., 2009); 'intuitive' (Moran, 2005), 'an Art' (van Manen, 1984) and 'insightful invention' (van Manen, 1990). Smith et al. (2009) emphasise that researchers need to stay close to the lived experience of the participants, as it is represented in the text, and consider what this experience means for this person in this context. This stage of analysis was dominated by an 'empathic hermeneutic', where I tried to see the experience through the participant's eyes. This was represented with direct quotes from the participant's extended narrative and descriptions that remained close to the text. I then developed a third table where I looked at the experience from a more systematically interpretive distance (Smith et al., 2009). This was represented with interpretive comments. These tables were amalgamated to represent key content areas, themes, sub-themes and conceptual metaphor; an illustration of this process is included in Appendix N.

As IPA researchers point out (Smith, 2004; Smith et al.,1999) this is a cyclical process that could proceed ad infinitum, so researchers must decide when a sufficiently convincing portrayal of the participant's lived experience has been achieved (Brocki & Wearden, 2006). At this stage I applied Braun and Clarke's (2006) criteria, asking: are the themes 'internally coherent, consistent, and distinctive'? Can the themes be linked back to sufficient examples in the data set? And has the process been systematic and thorough?

When developing connections between themes, I was looking for a narrative, that is themes that illustrated the participant's story and answered the question: What is the essence of the parent-school relationship for this individual participant? For each participant, as their narrative emerged, so too did 'families' of significant conceptual metaphors that captured the essence of their lived experience. At this stage, the extended narratives and metaphor families provided a holistic sense of the participant's lived experience.

This process was repeated for each participant, which is one practical reason IPA samples are small – it takes time and attention for the researcher to see each new case anew – to not look for the same themes in the next narrative that were highlighted in the last (Smith et al., 2009; Brocki & Wearden, 2006). Chapter 5 represents the outcomes of the interpretative process for each participant.

#### 3.3.10.4. Points of convergence and divergence – whole-part-whole across cases

The final level of interpretation aimed to make sense of the whole by synthesising the parts, that is, by exploring emergent patterns of commonality or points of convergence and divergence across cases (Eatough & Smith 2006). This phase aimed to remain close to the mothers' individual experiences while exploring aspects of their narratives that were common to the participants and by grouping their metaphors of lived experience into metaphor ‘families’. Appendices O and P illustrate two shared themes – Conditional Trust, and Concerns for Wellbeing and Wellbecoming. The question applied to this stage was, ‘is this an accurate depiction of what the experience was really like for these participants as a whole?’. The process of answering this question was one of looking for ‘gems’ (Smith, 2011), or insights into shared experiences. This resulted in three collective narratives – and the overarching metaphor families representing them – that are presented in Chapter 6 (See Appendix Q).

The final phase made cautious links between the collective narratives and existing research (Smith et al., 2006; Smith et al., 2009). The discussion relating to these conclusions is presented in Chapter 6.

The whole process of data interpretation is illustrated below in Figure 3.5.

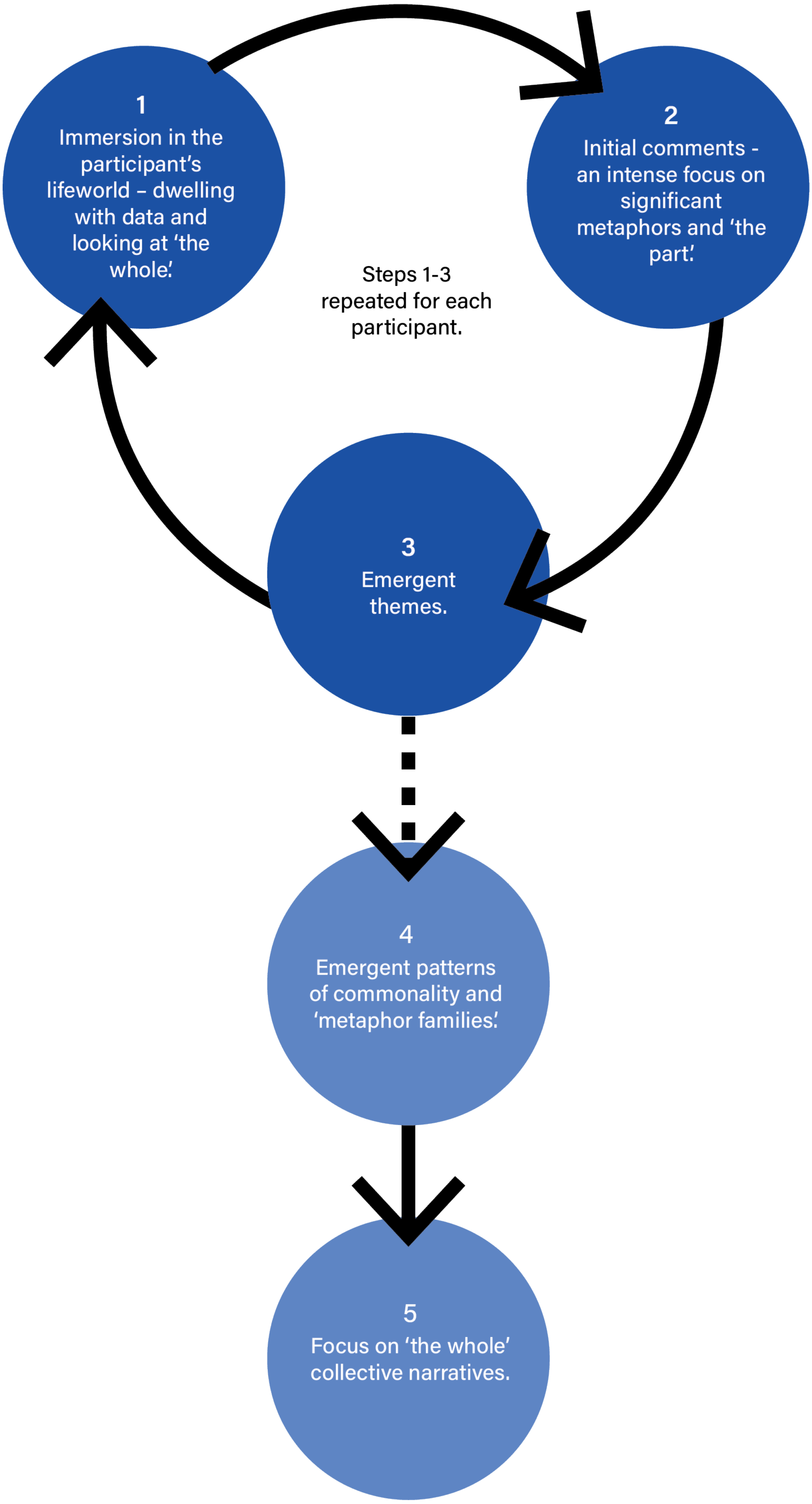


*Figure 3.5* Data analysis, adapted from Smith Jarman & Osborn (1999), Smith et al. (2009) and Palmer et al., (2010*)*

## 3.4. **Quality concerns and possible limitations**

IPA is one of a growing number of qualitative approaches and, although there might be ‘room in the tent’ for every one of the ‘new paradigm’ approaches (Denzin, 2017; Lincoln et al., 2011), admittance is conditional on demonstrating credibility in research design and process (Creswell & Miller, 2000; Merriam & Tisdell, 2016). Arguably, for newer qualitative research approaches, assuring trustworthiness is especially important. Due to their inherent epistemological and ontological assumptions, qualitative studies should not be judged by the same standards used to judge validity and veracity in quantitative studies (Holloway & Todres, 2007). However, Smith and colleagues (2009) emphasise the importance of validity and quality in IPA studies and suggest Yardley’s (2000) principles for assessing research quality in qualitative inquiry. These include sensitivity to context, closeness to data, commitment and rigour, transparency and coherence, and impact and importance.

*Sensitivity to context:* The relationship between participant and researcher and the position of the participants in the research were central to the current study, as evidenced in the data collection methods. Sensitivity to participant voice in the presentation of data determined the shape of Chapter 4; Chapter 5 aimed at an interpretation that was responsive to that voice, developed through a prolonged engagement with the data (Yardley, 2000). Sensitivity to context continued through the phases of data analysis and writing. The proximity between participant and research is a potentially limiting factor that makes it more difficult to retain a sense of objectivity about participant claims.

*Remaining close to data in both interpretation and written report*: IPA’s key difference as an interpretive phenomenological approach is the additional level of interpretation that links the final analysis to the existing literature (Smith, 2004; Smith et al., 2009). Arguably, this aspect of IPA allows for useful contributions to practice, however IPA’s first commitment is to a textual analysis that remains close to the data. The quality and accuracy of the interview data, as an expression of the participant’s lived experience, was a crucial starting point in the current study. Taking researcher accounts of data back to the participants for review, at varying stages of transcription, analysis and narrative development confirmed the accuracy of data collection (Creswell & Millar, 2000). In any hermeneutic task, there will be a point where participant input ceases; Gadamer's 'infinite' member checking is not practical or feasible (Smith, 2004). But in the current study, leaving the participants out of the data interpretation felt high-handed, given their degree of involvement in the research process. With a few interested participants I took van Manen's (1984) middle ground – we collaborated in the interpretation of themes to enter into a 'dialogic reflection' on the central phenomenon, asking, 'is this what the experience is really like?' (p.83). That this process was not followed with each participant is an inconsistent aspect of the research design that could be addressed in future studies.

Interpreting the participants' narratives via the lens of the conceptual metaphors they used to articulate experience and emotion aimed to provide an 'equivalence' of meaning (Seamon, 2000) between participant, researcher and reader. However, this interpretative lens should be treated with caution – many conceptual metaphors are culturally specific and may be sources of miscommunication (Sfard, 2014; Wallerstein, 2011).

*Commitment and rigour:* The current study aimed to demonstrate both a commitment to the paradigmatic assumptions of IPA's theoretical underpinnings (Creswell & Millar, 2000), and thoroughness in all stages of the study. This entailed gaining a satisfactory appreciation of the key principles of phenomenology, hermeneutics and idiography. And it meant adjusting the research focus in order to do justice to the participants' lived experiences and key concerns. I also demonstrated a commitment to researcher reflexivity by examining my own beliefs and assumptions, via the method of journaling, as they arose throughout the study (Eatough & Smith, 2017; Smith, 2007) (Appendix I).

*Rigour* in data collection meant revisiting themes, raised by the participants during the initial rounds of interviews, in subsequent conversations and emails. It also meant adding to the data stream when participants did not feel that they had adequately conveyed their story, even though this meant revisiting already-identified themes. Rigour in data analysis meant being thorough in the line-by-line identification of significant concepts, themes and sub-themes. It meant careful checking and cross checking across each participant's tables of experiential themes to find the points of congruity and difference. And it meant constantly shuffling and re-shuffling shared themes, in the manner of putting together a jigsaw puzzle, to find the emergent shared stories of these participants' experiences.

*Transparency and coherence:* Rigour is connected to demonstrating *transparency* throughout the account of the research project: in my reasoning behind decisions about the research design and in how I have carried out the research process itself; what Altheide and Johnson (1994) call 'validity-as-reflexive-accounting' (p. 489). Tables, diagrams and transcript and analysis extracts (as Appendices) support this attempt and provide a 'chain of evidence' that links all aspects of the research process (Smith et al., 2009). IPA studies are often conducted in teams and co-researchers provide reference points in assessing the quality of interpretation. However, researchers are also advised to use an 'independent audit' (Smith et al., 2009) whereby an outsider to the research project checks the final report against the research aims and chain of evidence. In the current study, my supervisors have fulfilled this role. Future single-researcher studies need to consider this aspect, as parties external to the research rarely have the same familiarity with the data.

*Coherence* can be thought of as 'methodological congruence' (Richards & Morse, 2012). In IPA, as in other phenomenological approaches, congruence and understanding develops through an iterative analysis and writing process (Smith et al., 2009; van Manen, 1984) and results in an interpretation that is 'plausible (to participants, co-analysts, supervisors, and general readers)' (Reid, Flowers & Larkin, 2005, p.20). A significant limitation of this aspect of IPA and other phenomenological studies lies in the experience and skill of the writer, a fact that is not always apparent until the final stages of the study.

*Impact and importance*: Smith et al. (2009) reiterate Yardley's (2000) point that the real test of research validity is whether the study 'tells the reader something interesting, important or useful' (p.183). This study shone a light on issues that mattered to the study participants and that send an important message for educators and education authorities. In presenting the participants' narratives in Chapter 4, I hoped that readers could connect with the participants' stories and empathise with their experiences. And, in viewing these stories through the lens of conceptual metaphors, I hoped that readers would see what I saw in my interpretation. However, a limitation of reliability with any interpretative account is the risk that writer and reader fail to achieve this ‘intersubjective corroboration’ (Seamon, 2000).

## 3.5. **Conclusion**

Given the inquiry focus and the researcher’s subjective experience, the research approach and methods discussed in this chapter were considered to be the most suited to exploring the research problem.

Interpretive Phenomenological Analysis (IPA) provides a way to understand two related phenomena: the ways in which neurodiverse adolescents interact with the social, learning and physical environments within the school context, from their parents’ perspective; and the ways in which parents subjectively experience their own interactions with their child’s educational contexts.

As methodology and method, IPA allows for an idiographic emphasis on participant stories that honours their role as co-researchers in the current study. It allows for new insights into the lived experiences of neurodiverse adolescents and their parents through researcher interpretation of those stories. And it allows for an explanatory connection between these stories, interpretations and existing research. The participant narratives, researcher interpretation and research connections form the basis for Chapters 4, 5 and 6, respectively.

# CHAPTER 4: PARTICIPANTS' NARRATIVES

## 4.1. Introduction

This chapter responds to the first two research questions posed in Chapter 1 and presents first person narratives that detail each mother's description of her child's experiences at school; her own experiences of participating in her child's education; and her interpretations of these experiences.

Chapter 3 explored IPA's perspective on 'reality' and its contribution, as a methodology, to understanding lived experience and what the world, what reality, is like for this person in this context. IPA accesses participants' lived experiences, and how they make sense of those experiences, via in-depth interviews and the stories that emerge from the interview encounter. Those stories that people tell about themselves and others constitute their reality, the identity and the 'life' they have constructed for themselves (Bruner, 2001; Reissman, 2005). Smith and colleagues (2009) state that, as an interpretivist approach, 'IPA is centrally concerned with meaning-making and the construction of a narrative is one way of making meaning.' (pp.196-197). There is an emphasis here on narratives as exercises in construction; as Bruner (1991) emphasises, narratives do not exist 'in some real world, waiting there patiently and eternally to be veridically mirrored in a text' (p.8).

In my conversations with the mothers who participated in the current study, I hoped to gain a better understanding of the phenomena of parenting and parent-school relationships through the stories they told about their lived experiences. However, as Chase (2003) explains, researchers tend to expect respondents to behave as informants who are filling in a verbal questionnaire: if researchers hope for 'stories rather than reports', then participants must be invited to share the story they want to tell. Chase (2003) suggests that the type of questions that amount to an invitation to share evolve from knowing the 'broad parameters of the other's story' (p. 284). In the current study I found that spending time with the participants and getting to know their story prior to interview resulted in the richly detailed and highly personal accounts presented in this chapter. Several participants affirmed Mishler's (1986) view of the interview response as a personally interpretive and sense-making act; they said that telling their story helped them to make sense of their experience and found it cathartic to talk about what they and their child went through: one commented that sharing her story had ‘helped me to accept and understand more of what we have gone through’; another felt that she had ‘a better sense of what happened, … some insight into the situation’ and another felt that sharing her story helped her to ‘come to terms with things I did or didn’t do at the time’.

These comments provided the rationale for this chapter’s organisation: McCormack (2000) argues that ‘ethical and accountable research demands that … we do not write research participants out of their lives’ (p.312). Not only do their stories evoke these participants’ lifeworlds, and hopefully resonate with the experience of others, but the chapter’s idiographic focus captures the individual claims and concerns of each participant while contextualising the ‘atomising’ effects of researcher interpretation in Chapters 5 and 6. However, because the desire to honour the individual story must also be balanced by chapter space, these narratives were abridged whilst retaining the original ‘sequence and consequence’ (Reissman, 2005, p.1) of the narrative structure and participant voice.

This chapter presents these abridged first person narratives that form the participants’ accounts of their lived experiences as parents of neurodiverse children: their accounts of their child’s interactions within the school’s social and academic settings; their perceptions of the barriers that these settings present to their child’s full participation at school; and their observations on how this impacted their child’s wellbeing.

## 4.2. **Michelle**

Michelle and her husband are both professionals and live in a middle-class suburb on the outskirts of Regional City. They have three children, and their daughter Cate is the eldest; their youngest child has a physical disability. Cate was diagnosed with ASD in primary school and experiences ongoing and significant anxiety related to her condition. At the time of the interview, Cate was nineteen and had completed school in the previous year. The events of Cate’s school years have had a significant impact on Michelle’s life, on her relationships with other parents and on her own perception of herself as a parent.

### 4.2.1. Michelle's narrative

Cate started out at a small state school; and I knew that there was something really different about her at the time, but I really just didn't know quite what to do. She didn't seem to get other children; she didn't connect with other children socially. She seemed to get very overexcited and she couldn't calm down. She would be talking to the other kids, but they wouldn't be listening to her. I noticed these things and I didn't know what was going on. She just didn't seem to get along.

There was a birthday party; there were [very few] girls in that grade and all of them got invited except for Cate. Cate really wanted to go and the mother rang me and said, 'oh well she had better come now' so I had to go, and it was so uncomfortable and so awful, and I just looked at this mother and I thought, 'how can you not see that that it is mean, to leave one girl out?'. It did make me feel less connected to that group of parents. At the end of Grade 3 I moved her to a larger school, I thought that maybe she just didn't get along with these girls. Maybe she just needed a bigger school, and it was all right for a little while, but the same problems occurred, the same thing, but at a bigger school.

By the time I left her first primary school, Cate was diagnosed with ADHD. The school didn't really provide advice but another mother at the school was an occupational therapist and did some tests on Cate. She gave me a report and that started everything off; I took Cate to see the paediatrician with no plan in mind. I had no idea, and I didn't really understand where I had to go, so the whole diagnosis of anything was very ad hoc.

The next school really didn't seem to believe that there was anything wrong with her. Even with her diagnosis, I didn't feel that they believed me, and I had several teachers say to me that they had gone out into the playground and had seen her with other children. Just because she was with other children, she wasn't necessarily playing with them or getting along with them. And I was very, very frustrated that they could not and would not see the difference there. It was a terrible, awful time – Grade 4, Grade 5 and halfway through Grade 6, when I took her out. I remember in Grade 6; Cate's photo was in the paper and a child had taken Cate's copy out of her desk and torn her face out of it. I was really upset, and I went up to the teacher to tell them; she was horrified, but she thought that all I wanted was the photo replaced. She said ‘I can get you a new copy. I’m really sorry’. I wasn’t upset about that, ‘It’s not the photo. How do you think that made her feel? That someone tore her face out of it; that she doesn’t belong?’

It was such a horrible thing to do, it was awful. After that, I took her out of school for six months to home school her, because I thought that would be a good thing to do. Being at home helped her confidence and how she felt about herself but [it] was much harder than I thought it would be. And I wanted her to get along with other children; she wanted to get along with other children. I don’t think I even still understood properly what the problem was. I was learning as well, at the same time. I thought her major issue was social and I couldn’t understand why she had been diagnosed with ADHD – it just didn’t seem to make sense to me. We did try medication for ADHD, but I don’t think it ever worked because it wasn’t the right thing for her.

In Grade 7 I changed paediatricians. She was diagnosed with Autistic Spectrum Disorder and anxiety along with that. So, by Grade 7, I knew what the issue was, and I was able to start getting her some help. I took her to a psychologist, and they helped her with her anxiety. I was still really concerned about her, but I felt I knew what we were dealing with then. And I had some sort of plan.

So, then I sent her to a local Catholic primary school for Grade 7. She had a good year there; she got a lot of social and emotional support. She would have friendship groups that she could invite people to go to and she had some learning support in the classroom. She still struggled academically even though she was really quite good at maths. But she struggled a lot with English and there’s a lot of English in maths. But she felt she was having some success. She got along well with her classroom teacher there and she had a very supportive P.E. teacher who made her feel as though trying was the most important thing. She hadn’t had that anywhere else and she always felt she was constantly failing.

I had no real idea about high schools, but I thought that because she’d had a good year, I would send her to a Catholic school. Religious ritual always calmed Cate down, so we wanted her to have that. There were family connections too and Cate really likes to feel some connection to where she's going, so those were the main reasons. The first year, the first half, wasn't too bad. And that's fairly typical of Cate, she's very social and *makes* friends easily, but she can't keep them. Because, for some reason teenage children seem to have some sort of radar for anyone that's different from them. I made sure she had the things the other kids had; I didn't want her to look different to compound her difference. But they seemed, from my observations, to sense that there was something that was different about her. They'd notice this after about a week or so and then she would start getting phased out of friendship groups.

And it seemed to me as though she was just slightly different from everyone else. She had a different manner of speaking; she'd talk a lot and they couldn't get a word in. I think that was some of her problem but sometimes I didn't even really know what it was. I used to think that if I could discover what was different about her and try and teach her not to do whatever it was that she was doing … but I never could. She just never got the social cues and social norms of being in a group, of being a girl. She just never got it. But I can't put it into words what she didn't get. She had to learn social skills like you have to learn the piano.

And whenever Cate found a group of friends to sit with, one of them would decide that she wasn't allowed to sit with them. I think that there were individual girls who liked her, but they were not strong enough to stand up to the other girls. So, she was never allowed to be part of a group for very long and she would always get thrown out. And I ran out of ways of making her feel better about it. How can you? And eventually I just decided that the treatment that she was getting was appalling and just because she's a teenage girl, who is supposed to be at school, why should she be putting up with this?

[Her high school] knew she had ASD and they were really on top of what that meant, for her. They had a Learning Support classroom, and she could go there at lunchtime; I think she was free to invite people, but I don't think they ever really wanted to come because they were with their friendship groups. They did really try to help her, but it was always about what strategies *she* could employ. All through Grade 8, Grade 9 and most of Grade 10 they would help her work through strategies, and she would try her hardest. But there came a point when it was all about what she was doing wrong. I know that sometimes she used to get the message wrong but not always. And a lot of the time it would be ‘maybe Cate is misinterpreting?’ and I’d try so hard to be on board, but she wasn’t all the time. I would sit there waiting for her to come out of school and I would see the other girls talk about her as soon as she walked past. I brought that up, but they said that I didn’t know what they were doing. And I understand that. But I sat outside the school every afternoon picking her up and I saw it every afternoon.

I think the teachers knew too; but there’s nothing that they can do. I don’t think they *could* address with the other girls what they were doing. They’re so subtle with the way that they do these things that there’s nothing that the teacher can grasp and say, ‘You did this’. There’s nothing for the teachers to cling to, to say ‘this is what’s happening’. It’s all very vague and like trying to grab a handful of fog. [The school] did talk about inclusion a lot, but it didn’t work; it doesn’t penetrate with these girls. They talk about bullying a lot; they talk about inclusion, but the girls aren’t stupid. They know what to do. I don’t know how but I’ve thought about it *so much*. The day that she left, this girl walked past in the corridor and gave Cate a filthy look. One of the teachers saw it and she said, ‘is that the sort of thing that happens?’ and Cate said, ‘every day’. But what can they do? Do they go to that girl’s parents and say ‘hey, your child gave this girl a dirty look’? They don’t care. If you’ve got a child that fits in anywhere, you’re just not thinking of those types of things.

To this day, Cate just is so resilient. She’d try every day. She would have a terrible day at school, but she would always wake up the next day and say, ‘I’m going to try again’. I cannot remember a day, until the day I took her out that she didn’t just get up and say, ‘no, I’m going to have a better day today. It will be fine’. I think she would have been a resilient person anyway, but she has learned that. She had to; she wouldn’t have been able to go on. She experienced anxiety every day, she actually did have to take medication for anxiety, and she learned to go on anyway. It was that serious that she knew that if she didn’t get up and try again every day that she would not be able to go on. I honestly didn’t think she thought she had much choice.

But it was *so* persistent and *so* part of her every day that she felt some sort of sub-human creature when she was walking around those corridors. And I had to take her out, it was awful. You could see her shrinking. I could see her losing weight. It was diminishing her every day. She was thrown out of another group and this time it just seemed to be the last straw for her. And I think it was because the girl said to her 'I want you to be in the group but none of the rest do' and they got the one girl that she liked to be the one to deliver the message. She came home, and she was upset; it used to upset me terribly, but I was used to this by now. And the next morning she got up like she normally does, she got into her sports uniform and I walked into the kitchen and she was on the ground in the kitchen, curled up near the pantry crying. My son actually picked her up; picked her physically up off the ground and he said, 'I don't think she can do this anymore. It's terrible'. And I kept her home that day and I never, ever sent her back.

She was much better when I took her out, I went through Distance Education. Academically I think she went down a bit because there wasn't the learning support, but she started to feel good again and I knew I was never going to send her back to school. I helped find a part-time job. I sent her to a youth group because I still wanted her to be with peers, and because she is very social. And she started going to Church again, which has always been very important to Cate. I think it helps her make sense of her situation and what she's been through. And they're very accepting people. I think the youth group knew that they were expected to include her, and it would be unacceptable not to. I've noticed it really strongly, with my other child, that children know that it is really inappropriate to exclude someone because of physical disability. She gets a lot of sympathy for having a physical disability that people can see. But honestly, Cate's disability has affected her life far more than it has affected my other child's life.

I have absolutely had to manage Cate; I'm in the habit of worrying and trying to look after her. She's had a really difficult time and I don't like saying that a lot because, really, she's been pretty lucky: she's got a great family, she's got a roof over her head, food to eat. But she's really had a difficult run. I cannot even imagine if you had this difficulty and your parents didn't do anything to help you.

I am a completely different person to what I think that I would have been; and that bothers me. It makes me sad that I have a lot of anxieties that I don't think I would have had. I get quite envious of other parents who have had these dream runs. I just feel different as a parent. I remember when our younger child was diagnosed with a physical disability, people spoke to me about the grief that you go through, and you grieve for the things that they might have been. No one ever spoke to me about that with Cate, and yet that's exactly what I've done. I still do feel different. I still don't connect very well with other parents because I feel that their experience is nothing like mine. I've never liked being involved in schools because I can't connect. I think, if I'd had a typical child or a typical journey, I would have been more involved. But it's put me off joining and it's really not that I don't like the other parents, I do. I just feel like I don't belong, that I don't make those same connections that the other parents make with each other.

Facebook makes it worse. I don't think there's anything wrong with parents being proud if their child has made [the] team. I don't think there's anything wrong with them shouting it from the rooftops. I don't think they mean anything by it but, if you've had a different journey, it's just really hard. I'm not part of the mainstream at all. And it does make me think about how different their experience has been from mine and it makes me feel very disconnected from them. I've tried to talk to other parents, but I can see straightaway they don't know what I'm talking about or really understand what I have been through. It's just completely different. I think that people who haven't had the same experience just believe that their children are doing well because they're good parents. I can see why they think that but then they look at other people whose children have these difficulties I do think, subconsciously, they think, 'Oh, we're doing this great job'. You can know something is not your fault in your head, but you just don't feel it in your day to day life. I really honestly felt, and illogically still feel, that it's somehow something to do with me. I actually know that that's not true, but I still do.

Constantly having to manage Cate's schooling wasn't comfortable for me. I think people assume that I was comfortable coming in to teachers and talking about things. I just *so* didn't want to do it! I didn't want to be there talking about these issues about my daughter. I knew what they thought … that I was over-protective. [The primary schools] made me feel as if I was being a pain. Every time I went up and said, 'Listen, there's a problem', it was almost as if they thought 'Oh, this mother is a helicopter mother and won't leave us alone.' I'd have given anything to drop her at the front gate and never worry what was going on in the school grounds. They seemed not to understand that I was genuinely concerned, I didn't want to be going in there and talking about it; I had to. I had to stand up for her. I had to advocate; I didn't want to, and that's still how I feel. It's not how I want to be; but when you're a parent, who's going to do it? I'd sit there and think, 'what if I just withdraw? What if I just let her go?' but I can't.

## 4.3. **Mary**

Mary and her husband are both professionals and live with their five children in a semi-rural area outside Regional City, Henry is their third child. I first spoke to Mary when Henry was in Year 7 at a Catholic high school in Regional City and we had follow-up interviews when he was in Years 8 and 9. I last spoke with Mary when Henry was in Year 10 and she was concerned about having to convey the same messages to the school, year after year, about the implications of Henry's diagnosis of ASD (Asperger's) and ADHD, with learning difficulties in literacy. Henry's older brother has a similar diagnosis and attended the same schools; therefore, Mary has had many years' experience of interacting with (often the same) medical and education professionals.

### 4.3.1. Mary's narrative

One of the main things we wanted in Year 7 was for Henry to be the same as the others in his class; to have a good experience and the same opportunities. We wanted him to be accepted as part of the group and for the teacher to see that he's trying to do his best. But when he can't achieve, that's when I have to step in to assist him to succeed.

This year [Year 9] I emailed all of Henry's teachers and I highlighted the main points of the IEP. And most important was good communication between parents and teachers. I say, 'I know he needs to learn to plan but there is so much less stress if we can get assignments completed on time and he feels some achievement'. And that's the most important outcome. All that I want is for him to be successful and complete the task with as little trauma as possible. A 'D' that they are putting in their best effort for is really important to me. It is what I consider as success. But for the school, a 'D' is a failure.

I’ve asked for email communication from teachers, but it doesn’t mean that it’s happening. Two teachers out of the nine have contacted me. Only one teacher had already contacted me, and he was fabulous. The good thing this year is that the new Principal and the Head of Learning Support have asked to be included in all communication. You really have to be very proactive if you want anything to happen. And the fact that it’s written in the IEP and they still don’t do it really makes you cross. We have wonderful IEP meetings, but I find as soon as I walk out of that meeting, I know that it *does not* transfer into the classrooms. Some of the teachers are on-board – you might have a younger teacher who is dynamic and looking for avenues – but you have some that really just won’t budge in the way they do things. Some of them will look at Henry, when something’s going wrong, as being stubborn and oppositional. And others will understand, so it is individual.

Each teacher will have different ideas on what’s good for Henry. It’s not, ‘we’re going to follow this plan’. That’s not something that is followed up, the best thing for your child. Though they do have to learn to be independent at some stage, there’s a big step from primary school to high school. You’ve got to hope for the best in high school. You’ve got to let them go and experience, and they might experience failure. And that transition from primary school to functioning really independently is actually quite a lengthy period of time. They really do need support all the way through. For example, in Science this year [Year 9] they let Henry choose to be on his own for a group task because he couldn’t work in a group. The teacher was very nice, but it wasn’t until I realised that he was on his own, and he was going to fail that assignment, that I realised I had to step in and assist him to get over the line. I didn’t realise that he was falling through the net until after the last assignment.

So, there’s moments like that and you don’t know what’s going on in high school because the communication is not there. You can ask for emails and things to be sent to you, but you still don’t really know how it’s going. Quite often you get a call from the school, and you go, ‘Oh no, what’s it going to be this time?’ It’s quite unusual to have a positive phone call. [Recently] Henry’s teacher [called] to let me know how he was doing. And to know what’s happening on the inside of that classroom is phenomenal.

There's no-one there that really helps them with the social thing of working in a group. They seem to focus a lot on social-emotional regulation. But they're just telling the kids how to manage their anger instead of trying to address the cause. They need to teach them organisational skills, life skills, so that they don't get to the point where they are in meltdown. It would be helpful if they identified that when these kids have a meltdown, that it's because of something else. Henry is a bit of a perfectionist and he might want to try and complete something his way, without asking for help, or explaining why he's taking so long. For example, in his Manual Arts class, he shut up shop and said he wasn't going to do it because he couldn't get it right; he'd given up. It has to be perfect. He just refused to complete the task and he had a bit of a meltdown.

And I've found that one-on-one contact is helpful if you can see something happening. For example, and I say this every year in the IEP, towards the end of term, for Henry, the wheels are going to fall off, especially when we're getting close to assessment. So, Weeks 1 – 6 we have a normal routine happening and all of a sudden, they change the routine in Weeks 7 – 8 and Henry usually falls apart because of the change and the increased workload in those last few weeks. All that stress just builds up, and they haven't prepared for it. I highlight it but there's not really the understanding of what happens when you take away timetables for a child on the Autism Spectrum. And generally, I get a phone call from the school. So, I now know to contact the school – you're generally trying to help that teacher, give them some strategies on how to cope with your child instead of the other way around.

We have had showing disrespect or not complying with the teacher's expectations. That example of deciding not to do an activity is common. One teacher said, 'I send him away for research for an assignment and he just sits there, and he doesn't do anything.' And you have to ask, does he not want to do the work, or does he have problems getting started? So, I've sat with that teacher and gone through the IEP and she has lots of passion, but she also has *lots* of other kids in that classroom. And they will always talk about aides being present to help, but the aides are not always able to figure out how to get Henry going.

We just did a psychology session with him the other day [Year 10] and we targeted organisation and asking for help. It would be five to seven years that we've been going to the educational psychologist with Henry. We've done lots of different things along the way. We've done speech pathology and we are just about to go back to the paediatrician because the school needs to have his diagnosis restated; the school would like a neat classification. I know funding is an important issue but having to do more testing is not necessarily helping Henry. I have to start with a new paediatrician, which will be difficult. It's all very foreign and I really don't want to do it. I'd rather just sweep that one under the carpet; it's not a good experience! I'm sure we'll go through the same sort of rigid testing and we'll discuss the same things – whether its anxiety or concentration or social-emotional needs. Sometimes it's harder if your child doesn't have one of those 'big needs', if they have an 'invisible need'. When something isn't quite right, but you can't put your finger on it and you're proving your case to the paediatrician, that your child has a need. Even if you get the paediatrician to agree with you, you're forever proving that you've got something that needs assistance.

I think that the teachers generally don't have a lot of time to fit in all the special needs of all the kids and it's not until you get to the IEP meeting that you actually sit down and nut out a real plan. [Until then] they seem to just fall in a big void. The IEP meeting is not until the end of Week 5 and even though the IEP from the year before is there, they don't seem to follow through. And so usually something goes wrong and I'll say, 'Have you been using the same strategies as last year?' Some are different teachers, but some are aware of his needs from previous years. I got a call this year, the Deputy Principal was saying, 'I've got Henry here' and I said, 'have they introduced the strategy from last year?' and he knew nothing of it. And it's not that I want any special treatment for Henry; I just want the class to be able to continue without any interruptions. So, if Henry can use a leave pass so there's not a meltdown or a blow-up then that teacher can continue teaching. He's supposed to show his leave pass and wait for acknowledgement but sometimes he can't. He just hasn't got the ability to stop. And he leaves … but he's not supposed to.

I encourage him to choose the right friendships or people to sit with. So, I do push in IEP meetings that they need to sit Henry near someone who is a stable influence and who can help him to stay on task and complete a project. He has got social friendships at school. I wouldn't say they would be flooding through the door, the friendships, but I would say that most of them are stable, solid. Henry is not one of the boys in the cool group, but I don't think it worries him. I don't think he has that reflective ability or level of awareness.

Sometimes he might do something repetitive or annoying. I had a parent pull me up the other day and I've had to have a word with Henry to make him aware of his behaviour that made the child unhappy. The mother was very unhappy and that makes me feel horrible! And I said to the mother, 'you can contact me any time. If you've got another issue just contact me.' Because I know, as a parent, if I can get Henry to see what's happening then I can help him. Even though it's sometimes not very nice. And I've been pushing the teachers, to tell me if anything like that is happening at school and they tell me 'Oh no, no, no, he's alright. He's doing fine'. At Parent-Teacher interviews I've asked every teacher 'Have you got any feedback? Do you have any issues? Please tell me if there's something that you need assistance with'. That's the really important thing, the social-emotional aspect. A parent-teacher interview is five minutes, so how much can you cover in five minutes on the academic *and* the social-emotional issues? You've got a child with needs, but you don't get the picture until the end of term when you have a five-minute meeting with the teacher. There needs to be more in the middle.

If something happens at school, then [Henry and I will] have a one on one conversation and just discuss what's gone down in the day. The big thing is to ask Henry what has happened for him, because it may not be the same as what happened for the teacher. Or, in the case of the child being annoyed by Henry, it is important to ask, 'what was that child doing to you?' because there was probably a lot more going on in the situation. So, you must listen to the whole story, not just one side. Sometimes they need that advocate, the person to say, 'hey, let's listen to both sides of the story' and that takes a lot of deep breathing and being confident where you stand. I've got better at that. Now, I'm very good at just staying calm but it is definitely not easy when your very first reaction as a parent would be to protect your child or make an excuse for them. I've learned not to react straightaway and to listen for more information.

You could easily become quite depressed when your child is not the same as everyone else, but I came to terms with not fitting in with the parent group at school a very long time ago. Your child might have one birthday in a term, or they might have one good friend that they connect with; they're not going to be someone that gets invited to everybody's place. And that's a huge thing for Henry – the whole rhythm of understanding how social etiquette works. Because 'friendships' is huge.

Currently we've got a square peg trying to go in a round hole – your child doesn't fit into the current education system, but this is what we've got to work with. And many times, I've thought of home schooling but, at the same time, this child needs social, emotional, relationships – all the other things for him to function well in society. So, there's more than just English and maths.

I probably do a fair bit of parental intervention. It is a lot of work and I know that's my number one job. I would say that managing Henry's education is pretty big and will be right through high school. Learning Support teachers have minimal time and resources to focus on your child so if you're not there managing them, you're pretty much leaving them on their own. You need to be the advocate for your child. Someone needs to take a stand for a child if they are unable to function. Someone with that insight into what's going on. And I think you're probably more around and present in a primary school than you are in a high school, so I would say that that it would be easier in primary than secondary to be an advocate.

I've created my own version of parent involvement, from having my older child to Henry who is going through what I see as the same things happening. If you don't contact the teachers, they just don't bother contacting you. But if we had some guidance on what a school [wants] parent involvement to be like, then that might break down some of the culture and walls that we have about a parent being too involved. We need a template for how teachers would like parents to engage with them; for how the parent can be a good advocate for their child.

I think you need to be a helicopter parent to a certain degree if you really want adjustments for your child. If you're not in there, making a stand and being an advocate for your child they won't be included. So, you really have to be brave and you have to be strong and you have to believe that what you're doing is the right thing for your child. Unfortunately, whenever we're parenting and going in to talk to teachers, we all remember back to our own schooling. So, you've just got to think, ‘ok, I’m here for my child’. So, it’s about staying calm and not being emotional about some of the things that happen, because sometimes, it’s really unfair what happens to kids. Like not having all the teachers on board; not understanding that you don’t press somebody’s buttons until they explode and run away.

If all those teachers knew what it was like to have a child with invisible needs … they can’t see it because they look just like normal children. So, for us, yes, we might come across as over-parenting, but these kids are going to continue having their poor working memory, their poor organisation, all these things you cannot see. And the bottom line is we want our children to have the opportunity to go to school, to complete tasks, have some achievement and make it to the other side.

## 4.4. Frances

My first interview with Frances took place when her son Forbes, one of a family of four children, was in Year 10 at a school in Regional City. Forbes received a diagnosis of Dyslexia in Year 5 and his school runs an educational program that targets SLDs. The parent school (The X School) is based in Canada. Forbes experienced acute anxiety related to his learning difficulties in several different educational settings; finding this school, which Frances calls their *salvation*, is the result of her determined efforts to have his learning issues recognised and addressed. Frances’ investment in Forbes’ education is highlighted by the family’s relocation from their farm, situated approximately 100 km from Regional City, so that Forbes could attend this school.

### 4.4.1. Frances’ narrative

Forbes is 15 and you can tell that he’s intelligent, but ever since he started school he’s really struggled with learning. In Grade 1 it was evident to me that he wasn’t making any progress, so I asked my friend, who was a teacher, ‘have I got cause for concern?’ and she said, ‘yes you do’. [His] school [was] very caring, but they didn’t have any resources for kids with special issues, so he repeated at the State School. They had a look at him, and they offered him some support programs. But it made no difference. He enjoyed sport but nothing to do with classwork. Socially he was fine; he was always well liked and had lots of friends. But he never liked school. He wanted to be at home, and I used to push him on the bus a lot of the time. Once he had to be removed off the bus by the police because he was trying to open the door while it was going because he was that upset. He was about eight.

We went to the hospital mental health unit, because the school thought that he was anxious. He was, but it was related to learning. So, the poor kid, he was that anxious about going there he wouldn't get out of the car. Finally, he came into the hallway, but he wouldn't come into the room. Their answer was to give us a program on how to parent. And we sat through it thinking, 'this is not helping our child. This is not the problem'.

Over the years we would have spent thousands of dollars on programs and testings. We took him to the developmental optometrists in Grade 1. And he would just cry all the time with [the exercises], it was probably just fuelling any anxiety that was already there. We went to the neuro-sensory unit in Regional City and there was an auditory processing problem; and we went to the Speech Pathologist.

At school, they were still trying these little things that weren't doing anything. And so, it kept going; every year the Learning Support lady would do some work with him. One day in Grade 3 she rang up and she said, 'I just wanted to let you know, Forbes got to reading level 25 and he is going to take off now. He's just going to grow wings and he's just going to take off. He's a reader, congratulations!'. And I was so excited, 'Oh, thank God!', and … nothing! After that, just nothing. We did have meetings with the school. The teachers knew there was something not right, but the Special Needs teacher was totally dismissive, as if I didn't know what I was talking about. And I felt like everything I was saying was falling on deaf ears, like they didn't believe me. When we enrolled him, I said to his teacher, 'do you think he has Dyslexia?' and she just dismissed it, 'Oh no. Don't be silly. He doesn't have Dyslexia, there's no such thing'. I think that Dyslexia is misunderstood, because people think that Dyslexia just means that you reverse the letters. They don't understand that it can actually mean that you just don't understand; that you can't read or do maths. Well, whatever you call it, there is an issue there that he couldn't learn like everyone else.

In Grade 5 I decided I was going to have him tested for Dyslexia because I felt like the school were just ignoring it and, as a mother, I knew there was something not quite right there. We knew he wasn't dumb and who else is going to advocate for your child? I think it's often kids with learning disabilities who become naughty because they're sitting in a classroom and someone there is speaking an alien language to them every day. So, we went to a Dyslexia testing service and once we got that report we started to get some things implemented. It was at that time that we had a meeting with the Guidance Officer who said it was a very comprehensive report and it supported everything that she had found. Forbes, another boy and a girl would get a teacher aide for half an hour a day to help them with some literacy and numeracy computer programs that the school and I had purchased.

We were having Forbes tutored as well, by my teacher friend. Any meetings we had after that, I would ask her to come with me, so they couldn't pull any language out that I wasn't understanding. So, I felt that I then had a bit of an advocate in the room with me. They probably weren't happy about that, but she was willing to come in and sometimes she helped me with the way I could ask the right questions. The impact of not being believed by teachers or having them downplay Forbes' diagnosis of Dyslexia made me frustrated. I know my child better than anyone and because I'm not believed by the State school system, they made me feel stupid. The teachers use 'teacher speak' and I found it difficult to put my arguments for Forbes forward, not being a teacher myself. It is frustrating, and I don't really think that they understood our frustration.

At the end of Grade 5 I was with some mums who were all talking about schooling. I mentioned that I had a son with Dyslexia and how that was difficult. One mum told me about 'The Ophthalmic Centre'; she'd heard of it through friends who'd had real success, so *she* went, and she'd seen a marked improvement. I'd never heard of it. She said that if you were remote you could go and do a two-week program. And I rang up and he did that program. On the Thursday of the last week, they asked me to go out and buy a chapter book. And I said, 'really?', because he was still reading those Level 25 books and he wasn't reading them well. So, the next day at the end of the lesson she said, 'Forbes, can you read this?' and he read it. It still brings tears to my eyes. I couldn't believe it. And then she said, 'read every day, for homework'. And he did. You'd still have to help him with the odd word, but that made a massive difference. He felt *amazing*. This program had given him some success. He had always wanted to read a book; we would get him audio books and he would listen over and over to them at night. And then once we [did that program] he read at night. And he has continued that.

When we came back, he could read, but he didn't always know the meaning. And his maths was still really, really bad – if the question said, 'what is the sum of 2 plus 2?' he didn't know what 'the sum of' meant. Grade 5 was obviously still a bit of a write-off because we knew then there was a problem, but it wasn't being fixed. His Grade 6 teacher was quite a good teacher and she would try and implement new ways of doing maths, but it didn't really help him.

And then it was like, what are we going to do for Grade 7? He was getting extremely anxious about going to high school because he didn't want to be dumb. It was a safe place in primary school because the three of them were pulled out each day. There was safety in numbers. And he was good at sport, he had something he looked forward to. And he was well liked. We didn't know whether to home-school or send him to the local high school. There was no question of boarding because he wouldn't have coped emotionally or academically. He didn't want to go on sleepovers, the last couple of years of primary school. He just wanted to be at home, and he would get upset when we talked about high school. He wanted to be home-schooled and I did look into it; I just thought 'I'm not the right person to teach this'. And I think they're better off to have social interaction.

I had looked into 'The X School' because I had read about it, and then I heard someone on the radio talking about how she'd gone to Canada with her kids. I was thinking 'Oh my God, that sounds so much like Forbes'. The radio station put me in contact with that lady and she gave me all these names and numbers and I did make some calls as to how much it would cost to go to Canada. But, short of selling the farm, there was no way. Plus, that meant that the family would have been split up. But I was desperate. Just desperate, thinking 'My God, there must be an answer. What's he going to do when he finishes school?' You've got to have a certificate or an OP to get into anything. How do you do a driving a test without being able to read? How do you get an apprenticeship? Lots of things.

So, we started at the local high school, which is where our older kids had gone. We had spoken to people there and they'd assured us that there were things in place there for the kids with Dyslexia and they'd be well looked after. Although I remember this one lady, when I told her that Forbes had Dyslexia, she just said 'don't be so stupid. There's no such thing!' and I just thought, 'oh my God I hope you never get her!'

The high school had a big new trade centre and we thought that would be a good thing for him. And with a bit more maturity, maybe things would happen. Moving rooms and timetables and things like that didn't concern Forbes. Plus, he had lots of friends from the primary school and he knew some kids from other schools too. But then it would come to homework and he couldn't do it, there were no modifications. None. In the end, there was absolutely no help at all even though he was on a modified program in the Primary school and we told that he was ear-marked for support. There was no communication: any file that had gone over had not been distributed to any teachers. They knew nothing. We found that out at the parent-teacher interviews at the end of Term one; they would say, 'Oh, we were unaware that he had Dyslexia'.

And he would come home crying every day and saying 'I'm dumb. I'm the dumbest in the class. I'm so stupid I just want to kill myself'. He just didn't want to go to school and it's terrible, because you knew that he wasn't dumb. What do you do? They start putting them into detention because they haven't done the work, because they can't do the work; they're punishing them for something that's not really their fault.

He was really, really unhappy and I was still corresponding with the mother [from the radio]. Just before high school, we had gone down to a school with the Canadian Program at the coast, and I was told that we could go on the waiting list. And it was a nice school, but we just thought, 'how would we make this work? This is so far away from where we live, we'd have to rent'. My work was up here, and we still had the farm. Then the mum rang and said, 'have you heard that it's coming to Regional City?'. We were at that point where we thought, 'let's just give it a go and see what happens'. So, we came down and had testing. This was Grade 8 and I think we only enrolled a few weeks before it started.

Forbes was upset about the move; he didn't want to leave his friends. Plus, there was a bit of a stigma, being pulled out and put in a special school. Because he would have to explain to friends where he was going. I think he just told them 'I'm going to a school for Dyslexia'. So, we started, and he was anxious, so we had lots of tears over the holidays. And then we just worked through those first couple of weeks; he'd still say 'I'm only there for a year. I'm just doing this year and then I'm going back'. We drove in and out every day. I would drive in in the mornings and back and then either Forbes' father or brother would drive in in the afternoon and back. Or sometimes I'd have the afternoon shift. His aunt in town offered to have him, but Forbes wanted to be home all the time. It got better. You could see little changes where he'd made friends and wanted to get to school a bit earlier to be on the basketball court. So, they were all good signs and, he pretty much did the homework without complaint; he knew that he was there for a reason. The second year came, and we decided to move in [to regional City].

The first year the only real anxiety we had, I guess, was friends and an assignment – they were wanting him to stand up in front of everyone and present and that makes him anxious because he couldn't read it. He can read a book at night time but if you ask him to read a newspaper article or whatever, there's still words there that would halt him. We just advocated for Forbes, that it was stressful, and it was making him anxious. And the Program teacher was really good and advocated for him as well. When we first went, he didn't have to do maths and English – they didn't want him to do subjects that were going to cause him any anxiety or stress. They wanted him to do subjects that he could achieve in and that would boost his self-confidence. He's more positive and he goes to school without complaint these days.

Finding out about 'The Ophthalmic Centre' was pure chance, and the Canadian Program, I might have first come across that at the Dyslexia testing services because they say, 'read this book, read that book!'. But it was not from the school. Without that network God knows where we'd be.

## 4.5. **Eileen**

I first spoke with Eileen when her daughter Emily was in Year 10 at a Catholic Education girls' high school in Regional City. Emily is the youngest child in a large, middle class family and Eileen has stayed home to raise her family. Emily's eventual diagnosis, in late primary school, with NVLD was both the culmination of Eileen's efforts to understand the significance of Emily's apparent learning issues and increasing anxiety at school, and the beginning of a new chapter in her schooling.

### 4.5.1. Eileen's narrative

It was probably not until we got to pre-school that Emily's problems started to evolve, she was always very social, and she went to Kindy happily. Her spatial issues were not obvious to me. The Kindy teacher would say things like, 'she's not good with scissors', but she was left-handed, and I'd say, 'well she doesn't use scissors at home'. I didn't click but looking back, those things are probably more meaningful than they were to me then.

She seemed to go through pre-school quite fine, in the end of the year report there were no obvious problems with her keeping up. She got to Grade 1, and all our other kids went through without any problems, but she just wasn't learning anything. She wasn't reading, and she couldn't do maths to save herself. It wasn't until the end of the year that the teacher said, 'I've got real concerns about Emily. She's just not progressing like the other kids'. And she said 'Look, I just thought she was being lazy and not trying. I sort of yell at her to try and get her going and she'd just look at me with this fear in her eyes'. She just wasn't learning anything, but nothing was ever done or suggested.

She got to Grade 2 and early in the year her teacher called me in and said, 'Emily doesn't seem to be able to pick out anything on the board. She's obviously got some issues and I'd like a WISC [Wechsler Intelligence Scale for Children] test done on her'. And then the psychologist said to me afterwards, 'I have no idea how to decipher this, she has scored so low. But I know from spending time with she's not like that'. Then she went away, and nothing was ever done about it. So that was it. And she was with this lovely teacher who she loved, and she had a beautiful year. But I remember going up for a parent day and we had to make a 'me' box to put all their special things in, and she was so excited I was there. And I just watched all the other kids, and I did everything. Emily couldn't get herself organised; she didn't know what to do. At this stage I had noticed very poor organisation; I helped her with everything. I used to go to school swimming, she could never get her togs on. The teachers were, ‘quick, quick, quick’ and so I used to help her, thinking she’ll eventually get the idea. But she was very slow, couldn’t tie her shoelaces, couldn’t get her buttons done up.

And she cried every morning. It turned out she hated the obstacle course that they used to do every morning. She has spatial issues and hates playgrounds. She’s not good at team sports – she’s not good at working out what’s going on in the game. And she would not go to birthday parties because of the party games. She didn’t know what was ahead, what was required of her. She’d often leave the invitation in the bag and not tell you. I put her into netball; I thought, ‘It’s perfect, they’ll all start at the same level’, and by week four the other kids all knew which way to throw the ball and which way that they were running. She just never, never got it. She only really went for the ice block at the end. It was a very nurturing group to be in, and they’d always put her on for a while, but she just wasn’t in the game at all.

And as a parent you don’t know whether, ‘If I give in to them now, will they never do that again? Have I got to push them and show them that it is ok?’. It’s really hard to know how much to push them when their norm is always pushing themselves. And the pressure that they put themselves under, all the time. You want to lift that off their shoulders. And, the constant questions, all the time. That should have triggered me to anxiety when she was in primary school: ‘Mum, are you going to be there when I get out? Make sure you’re there at 3.00’. She’d say that 40 times before you’d get to school.

In Grade 3 she had a teacher who had taught all the other kids and she said that he was the best because he let her cheat. She was under the radar all year; nothing happened for her and he just let her copy off the other kids’ work. He’d say, ‘Emily isn’t like the other kids’. I suppose they’ve got big classes.

In Year 4 we decided to go for the Year 4/5 multi-age class, which had a lovely young teacher. So, she sat there in Year 4 watching what the Year 5’s were doing, and she was terrified of the next year. She couldn’t even do what she was doing this year. She had started with some learning support at school, but it wasn’t until later in primary school, with IEP meetings, that communication was better. She used to get pulled out for a remedial reading group, but she still wasn't reading fluently, and her maths was abysmal so I put her into tutoring, which was the worst thing I could have done.

She couldn't learn her tables; we used to walk up to school every day, go over our times tables … next day she still wouldn't know them. So, then I got tapes, but she still didn't get it. She couldn't remember her sight words, it didn't click. So, I took her to a speech pathologist, and she helped her tremendously. She got her on track with the reading, her comprehension is abysmal, but she can read. You just want her to get to a level where she can exist in life. Earlier I'd taken her to a 'prepare your kid for school' group. Emily was at school, but she was still way behind. They tried with her reading, but it didn't really help, and it was such hard work. This was all out of school hours and I also got another tutor to help her on Saturday mornings. We put all this energy into her, and it was just wearing her out.

I felt very alone with her problems in primary school, I wasn't sure where to get professional help and no suggestions were offered. One of her tutors recommended kinesiology so, we took her to that, and she said, 'Oh, you're just going to notice her come alive. She's just going to notice so many things', but it didn't really happen, and her schoolwork certainly didn't improve. After many hundreds of dollars, you think, 'should spend we be spending our money in a better way?'. But we were trying to find somewhere, we would have been happy with anything.

All through school, Emily hadn't really slept but then she started to get horrendous nightmares and night terrors. She'd sleepwalk and she'd scream and scream; and you'd just sit with her; it could take [more than] an hour. She couldn't remember them the next day but at night she'd talk about things at school, things that were going to happen. It was all school and the pressure of life. This was every night, sometimes twice a night; she was so tired. I went to school one day and I was quite upset because she'd just had one of these nights and she didn't want to go; she never wanted to go to school and she was always sick. I went in to see the Learning Support teacher and then the School Counsellor said, 'I think we'll repeat the WISC test', and it was done. Four years later. She rang me and said, 'Look you've got to come in and see me. I think there's a real problem with Emily and you need to get her to a paediatrician. I think Emily's got this Non-Verbal Learning Disorder and you definitely need to get some professional help'. I had thought, 'I can't take her to a paediatrician, what will they say to 'she cries; she screams all night?'. I wasn't really sure what to do with her, but this developmental paediatrician was perfect.

He said 'you're not going to want to hear this diagnosis. It's Non-Verbal Learning Disorder; it's just one of these things that happens'. He said, 'she'll just sort of trail along behind her classmates until they get to about Grade 6 and then they'll just soar, and she won't. She'll just sort of plateau' and that's exactly what's happened. And he said to her 'Oh you poor little thing. You must just sit there at school and it all just goes over your head. It must just all whirl around you all day. You must be so exhausted from how you feel' and she just came out and said, 'He's the first person who's really got me. He seems to understand how I am'. And she's always just loved going to see him because he just got her, and he'd always implement programs to help her at school. And if you go to a school and say, 'the paediatrician said…' all of a sudden, you can cross barriers that you can't always as a parent. A paediatric diagnosis is a golden key; you get noticed and you get listened to. But there was still academic pressure; even with the diagnosis, teachers are programmed to give homework. High school has finally got it and Emily does her homework at school, with help.

And he said it's got a high anxiety component with it and that can lead to depression. So, he said, the most important thing for Emily, is to get the mental health side of things under control. [She started taking] medication in Grade 6 or 7 and it changed her life. The second night she took it, she slept through the night, which was unheard of. And from then on, she pretty much sleeps unless school is going back for the term or there is a worry. When she was younger, when there was some school camp, or some talk she had to give at school, that would override the medication and she'd start back with the nightmares and the screaming. But it's pretty much kept her on keel; she never forgets to take it because she feels better with it. And she did feel awful.

Deciding on a high school was easy. I'd always known [Emily's high school] was a great school, very caring. The paediatrician said, 'go somewhere that is very nurturing, with a broad curriculum'. So, it ticked both boxes very well and it's been wonderful. But I was terrified. I just thought 'how on earth will she cope with all these different classroom changes, different teachers? It’s just going to be a nightmare for her. She’s just going to feel such a fish out of water’. I thought, ‘do I have to go and advocate to each teacher, every time?’. You’ve just got to be the advocate for your child, and you want to be, but you feel like that painful parent. I don’t think I ever had to go up to a teacher with any of the other kids and then I felt like I was always up at the primary school: ‘she can’t complete this; we haven’t done this; she can’t do her homework; she’s been crying all night’. You’re always up there saying ‘this is why it’s not done’ and it was always her fear that she’d be in trouble because she hadn’t completed what she was supposed to do. So, we’d say ‘it’s ok, I’ll go and talk to the teacher’. That was the only way you could get her up to school.

Emily doesn’t have a behavioural problem, she does what she’s told, and she’ll fit in. It’s just that she needs to be directed to keep going. Her pastoral care group meets every morning before school starts and puts them on the right track for the day. First of all, they put her with a maths teacher and the Learning Support teacher said, ‘he is very organised, and I think he will be able to help Emily’ and I thought ‘Oh, I think nurturing above motivation will work better for Emily’. So they swapped her PC to a woman whom she likes, and they’ve kept her with her. She’s comfortable with Learning Support, it’s all working really well, and the teachers have just been great. I rarely have to ring up. Except like before school went back this year, she had nightmares and all night she was up, down, couldn’t sleep. She was worried that her teachers and aides were changing, her subjects would change. But then she went off to school and she’s been fine now.

All through primary school, on Sunday when 60 Minutes started, that clock ticking, Emily would burst into tears. It was always: ‘oh no, I’ve got to go to school!’. Now we get through 60 Minutes without tears and it’s wonderful! We still have the psychologist, although now we hardly ever go. But I realised recently that she still does have that deep anxiety that’s always underlying. And so, although school is going well, you think it’s still all there, it’s just under the surface but you tend to forget because she is coping better now. She’s a changed child, instead of leaving the house at twenty-eight past to get to school at 8.30 we can leave at 8.00 because she’s all organised.

She hasn't really encountered any harassment or bullying. There's some group fractures at the moment but it's always the same with the girls and she's interested, but she's not a part of it at all. She knows the kids have got boyfriends and do all these things, but she doesn't go to socials. She just comes home on the weekends and school's finished and that's it. She's always had friends and now the Learning Support group are her best friends. She texts her friends all the time, but they don't see each other. And the texting has been fantastic. Because every morning they text each other and that makes her get out of bed.

The difference between her and the other girls in the Grade has become obvious over the years, she's not working on the same level. But it's not really a source of anxiety because she doesn't want to do what they're doing; it's too hard. For maths and English, she's in Learning Support but for other things she's in the mainstream, on her own program. The Learning Support teacher emails all the teachers so everything she does is modified. And she's got the aides there with her; she loves the aides. A lot of her work is on the computer and she said the other kids don't even know what she's doing, they don't even know its modified. She thinks the other kids think she's doing what they're doing. I don't know what she thinks the aide is doing there! Probably 99% of the time she doesn't have homework, just because the paediatrician doesn't believe in homework until they're in Grade 11. It's just that golden key again. And, as a parent, you'd be pushing her to do her homework, it was just horrible, and you'd end up doing it for her anyway because she didn't know what she was doing.

We have the two IEP meetings every year, which are good, and her social-emotional well-being is always brought up. The school is very aware. We're putting no pressure on her academically; we're more interested in her mental health and wellbeing. She doesn't need to go to the school counsellor anymore, she can advocate for herself now. She feels so comfortable with the Learning Support family, that she'll go and tell them her worries herself and they seem to just sort everything out for her. [The school is] very approachable, probably because we've been there a long time and [know] a lot of the teachers. Communication is very easy, especially with email. You don't feel like you're intrusive or interrupting teachers when it's not appropriate.

I’ve always felt Emily will be right. You hope she gets a job, and she talks about learning to drive and I think ‘Oh my goodness!’. But she’s got this family that will just nurture her and long term, there will always be someone around to watch over her.

## 4.6. **Eloise**

Eloise and her family live on a cattle property in a remote rural area and distance has been an issue in her son Rory’s learning journey. Eloise home-schooled her three children and then they went to the local state school in the small town closest to their property. The nearest regional centre is over 150 kilometres away and the closest major centre is Regional City, 400 kilometres away; Rory now attends a large urban boys’ boarding school in Brisbane. He was diagnosed with Dyslexia in Grade 5 but identifying and supporting his learning issues to this point was exacerbated by the limited educational and support services in their district.

### 4.6.1. Eloise’s narrative

Rory is 14, so he’s in Year 9 this year. He did pre-school and Prep on Distance Ed. with me as the home tutor; the school in town is 50 kilometres one way, no school bus and about 25 in the school. He was the only one in his year level, in the multi-age class, for a lot of his years.

When Rory was being home-schooled, I noticed a couple of things, like he wouldn’t choose which hand he was going to write with. But it probably wasn’t until Year One that I started worrying because he just wasn’t going anywhere with his reading. And his lovely, fresh-out-of-uni teacher, who was teaching Prep to Year 4 in a multi-age classroom would just say, ‘oh look, it will click’. I think, by the time she’d said that in Prep and in Year 1 *and* in Year 2, I did start worrying. It was Year 2 or 3 when we first got to see the Guidance Officer that would come to school once a semester and they started doing some testing on him. In Year 3 a new teacher came, absolutely fabulous, and she really got stuck into things then, with getting help, having an IEP written, those sorts of things.

Rory had absolutely no memory retention. We would do times tables and spelling in the car; I’d have CDs playing with all those sorts of things. We’d do ‘was’ in the car

– ‘spell “was” Rory’, ‘W.A.S; W.A.S’ then two minutes later, ‘spell “was” Rory’, ‘S.A.W, S.A.W’.

It’s such a small school, a lot of us had [several] children at the school so there might have been eight or ten families. That was about it. So, he didn’t do NAPLAN tests; I excluded him from those because he was often the only one in his year levels. All the data comes back to the school, and we’d go through the data at P & C meetings and everyone could see, ‘Oh well that’s obviously Rory’s results’. I probably didn’t discuss my concerns for Rory with other parents; but I think a lot of parents could see it. And I’m sure the kids would go home and say, ‘Rory couldn’t do this, and Rory couldn’t do that’. Being in a small school, I don’t think it worried him all that much. And Rory’s very lucky in lots of respects, he’s very sociable; he has a great sense of humour; he’s very sporty. He has a lot of strengths. I don’t think the perception of the children worried him at all until he got older. I could start seeing it in about Year 5 and 6. Particularly when he was the eldest in the school but probably doing Year 4 work, that would have been really obvious, in a small classroom. This was one of the reasons we did the move to Regional City Independent School for him for Year 7; there were quite a few kids like him there, in his Year 7 class. He was the only one in the school at home. But he definitely felt secure in that environment. And it was easy for him to be there. We had an amazing staff to student ratio, and he was always getting lots of help. And I think, a lot of the times he was over-assisted – when it came to the crunch for him to do an exam, he didn’t know what to do on his own. He still needed that support behind him.

When Rory was in Year 4, we had a dreadful situation. He had moved up into the senior class and so he had the teaching Principal, who caused a lot of problems in the entire school, and it was a very stressful year for everybody. She ended up leaving in Term 3 but prior to that she just whittled away Rory’s confidence terribly. She’d make him stand up and read in front of the class; she would hold up his writing and show everybody how bad it was, those sorts of things. Just not supportive in any way at all. She wouldn’t recognise his IEP. She spent the first month or so saying she hadn’t got around to looking at it and by the end of the first term she said, ‘I don’t agree with it. I’m not following it’.

The Guidance Officer wrote the IEP with us. And Rory had seen occupational therapists and a speech pathologist who had been involved in it as well, but she refused to go with it. She didn't agree with the speaking in front of the class; the sitting up the front of the class; the amount of teacher aide time he was supposed to be having. If the specific goal was reading comprehension, then he was supposed to have it read to him or have an audio book. She said no to all those things. The impact on Rory was dreadful, his reading levels went from about a 12 on the PMI reading groups down to a 7 or 8 that year. He just lost his confidence in everything, even in sport. He'd get really teary, over all sorts of things. And he just generally did not want to go to school. I mean he's very social, he always wanted to go to school, that was never a worry with him but all of a sudden, he didn't want to go.

As a parent, it made me feel completely out of control of the whole situation … and furious. I thought, to start with, 'Wow, we've got everything documented now so that whenever he gets a new teacher it will all be ok. They'll come in and they'll know what he needs'. And it got to the stage of 'what do we do?'. So, we spoke to her and we didn't get anything happening there, so I went further. It wasn't easy to find the right way to go about it, at the start but once I got on to the right people it was ok. And I suppose I was probably lucky in some ways, I was within the P & C and I did speak to P & Cs Queensland and a few people like that, as well, about what's the best way to deal with it all. I was definitely advocating for Rory and for the rest of the students. I felt if she's doing this to him then what's happening for everybody else in the school?

When she left, we were thinking at that point of moving for school. But I asked the Director of Education… if I could have the name of the person who's coming because we need to make some decisions. And he gave it to me. And I rang [the new Principal]. I got to know him very well that year. And he was wonderful. With the new Principal we saw amazing change. He got all the kids right into their sport and sport was Rory's strength. So, the Principal coached him, and he did really well at district sports, regional sports and that just showed in the classroom. In Year 5 we went to a developmental paediatric group. The Principal agreed with us that we should do something, and he said, 'I'll do anything to support you that I need to'. Their educational psychologist was great; he did quite a bit of testing and he suggested some programs. It was a *huge* amount of work for me and for Rory. The Principal had incorporated quite a bit of it into the classroom, he said, 'It's probably going to help other kids as well', which was great. But it was still a lot of work. I'd have weekly teleconferences with the educational psychologist, and we'd have to have a certain amount done and there'd be a certain percentage of testing.

But I think it helped; we saw improvements in his comprehension and reading but it did get a bit cumbersome at times with two other children and the driving in and out. It became a chore towards the end. And it wasn't cheap either, it was thousands. Plus, visits to Brisbane. And sometimes, towards the end particularly, we'd fly and try and make it a bit more fun. But it was only really that twelve months that we really focused on it. And during that time, I thought, 'I really need to hand this over. I'm not a teacher!'. And if you have a child who needs extra help, [therapy] is definitely an added burden for rural parents. The speech pathologist, Guidance Officer, occupational therapist would all come once a semester. If you saw the same one twice you were very lucky, so continuity was definitely a problem and there was definitely a lot more follow-up for parents than usual. And they didn't ever come up with a diagnosis; I don't think they ever spent enough time with him. They didn't ever do any formal testing; they'd just come and do a few little programs. Rory had no formal diagnosis; he wasn't formally diagnosed with Dyslexia until we went to the educational psychologist.

Year 5 and 6 were fabulous years but Rory had already had three years on his own in his year level. He would eventually go on to boarding school, but we could see that he needed the support of me being with him for one year. So, we came to Regional City Independent School and he did Year 7. And it is the best thing we could have done. It just needed that little bit of a stepping stone. I think the small numbers were an advantage; not as small as he was used to but smaller numbers than the boarding school in Brisbane. I think it was a softer way of doing it, easing him through things. I could see towards the end of Year 7 he was ready; he'd become more independent. I was very focused on doing that; even though he was living with me I was trying to encourage that. He'd spend a lot of time with the boarders and they've got a great system where you can do day-boarding and he'd do that quite a lot. It worked really well. And he had a very experienced teacher, no child is new to him.

Regional City Independent School wanted to start again with the IEP process although I gave them a copy. I wouldn't rave about the learning support there, but I was probably trying to wean him off having too much assistance anyway. I think we were just lucky to get the right teacher. I think his year at that school was more about him finding his feet socially and emotionally, finding his independence with his academic work, still with that bit of guidance. I think that was more what it was about than actually having a massive year of learning support. I think we sort of got to the stage where he was a bit over it all and he wasn't going to take too much more of that. And I think if I had been hounding him too much more that could have caused problems too.

And I couldn't be happier with what's happening at his Brisbane boarding school now. He's getting a great level of support, particularly in the boarding house; they have tutors and I employ a tutor one hour a week who really just helps him with organisation when I can't be doing that. So, although I try and keep on top of most of it, I try and step away too. But I had to make sure that there were people there taking over from me. They suggested for him to be on learning support at his new boarding school he would have to have an educational psychologist review. So, after much discussion, and another couple of thousand dollars, we had a report done which worked out really well. The report basically repeats his IEP plus extended time for exams and assignments. I would have really liked, and I'm still having issues on this one, to say, the exam to be read. Because, in his Science exam last year he said 'Mum, I could have done really well on it, but I spent all my time trying to read it.' And I thought, he's not being tested on his Science knowledge, he's being tested on his reading.

I've spoken to him about Year 9 NAPLAN; it's coming up and I don't know whether to exclude him or not. He said, 'Mum, if I'm excluded, everyone is going to know.' It's important for him to be with everybody and I'm thinking the same with his exam situation; is everybody going to say, 'why aren't you in here with us? Why are you off doing something else?' It's the same with peer tutoring, I kept pressuring him last year about going. He said, 'Mum, I don't want them to know I can't read these things. I don't want my classmates to know that I'm struggling to read it'. Whereas if he's got an adult with him doing tutoring, it's ok. And he just wants to be like everybody else, so now I’m thinking, if I do too much excluding him from different things the other boys are going to pick up on that and he obviously doesn’t want that. He’s still very sporty, very social and he has a great group of mates. So, the learning issues only affect him in the classroom. I don’t think there’s a bottom maths class, so everybody knows, ‘Oh, they’re the ones who struggle’. Which I wonder about in some ways, but I think he’s getting enough outside help for that to be ok, for them to say ‘well we’re all in the same class. We might not all be the same ability levels but we’re all in the same class’.

Rory would definitely have struggled with the size of this school if he had gone straight into boarding in Year 7. I thought if he had to deal with going to a bigger school, boarding, being away from me who’d been doing so much of his support, had been his support network, all at once; I think he would have crumbled. There would have been too many changes at once. And I think he’s getting so much better at processing things and not being overwhelmed in the classroom by, ‘We’ll do this, this, and this, and then that is going to happen, and then that’s going to happen …’.

I’m on very familiar terms with the Head of Middle School and, usually once a semester, [we] discuss how things are going. So, I’m still very much keeping my finger on it. [At] the last meeting I said, ‘I’m at a distance, I need you to be on top of this’. But I’m trying not to be the helicopter mother. I’m very aware of that. And it really has been smooth sailing. I spent 13 years of Rory’s life lying awake worrying about him. It’s a relief. And sometimes I think to myself, ‘Oh, Geez, should I be more on top of this?’ But I think it’s ok and sometimes you have to let things run their course. But I worry about what the world will be like for them when they finish school too. I think, ‘well what are they going to do?’. Hopefully, Rory will get a trade, but I think the main thing we wanted for Rory is to have a good experience; so that he’s not completely scarred by the experience of school. I just had this constant need to know that he’s going to be ok to get his driver’s licence, that he’s going to be ok to do all sorts of things you need to do as an adult. And I look at him now and I think ‘he’s going to be ok’. Whereas for a long time I didn’t think that.

## 4.7. **Conclusion**

In this chapter, the participants' narratives communicated their child's educational and social experiences and their own parental experiences. The narratives also communicated these mothers' attempts to make sense of, and contextualise, what were often painful and challenging experiences against what they know about their child and themselves. Sometimes they struggled to find the words to express how they felt; their use of metaphor at these points allowed them to articulate the complex emotions and abstract ideas associated with child rearing and mothering.

Lakoff and Johnson (1980/2003, 1999) suggest the embodied origin of conceptual metaphors is integral to how we make sense of our experiences and this is evident in the way these mothers describe their interactions with education and medical professionals. There is also a sense of the original physical connection between mother and child that is retained in the language these mothers used to make sense of their child's anxieties, their own supportive efforts and the challenges associated with everyday expectations of adolescent independence. Chapter 5 explores the underlying meanings attached to these descriptions, metaphorical expressions and organising conceptual metaphors.

Chapter 5 also explores the way the participants each perceived the various interactions, at a micro- and meso-systemic level that have impacted their child's developmental outcomes. These include their child's interaction with teachers, other students, the learning environment and the school's physical environment. And they include the participants' interactions with significant persons in their child's environments such as education, medical, mental health and allied health professionals.

# CHAPTER 5: INTERPRETING THE NARRATIVES

## 5.1. Introduction

IPA asks, ‘what is this experience like for this person?’ and explores this question through a double hermeneutic approach. The previous chapter presented the stories the participants told while ‘trying to make sense of their world’; this chapter presents the researcher’s attempts to ‘make sense of the participants trying to make sense of their world’ (Smith & Osborn, 2003, p. 51).

In the current study, conceptual metaphors provided a shared language between researcher and participant, and a window into the participants’ lifeworlds and sense-making activities. Conceptual metaphors have the power to ‘translate’ abstract ideas and complex emotions into more concrete terms and help to communicate experiences that may not have been shared by the reader, such as parenting a neurodiverse child, in terms of universally familiar images and experiences. Not every reader will understand what it means to have learning difficulties, but most readers share the embodied experience of being *left behind*.

As the participants’ narratives illustrate, common understandings of education are organised around the LEARNING IS A JOURNEY metaphor. Describing a child as being *left behind* on the *learning journey* evokes all the importance we place on educational achievement in the 21st Century; and all the associated disadvantages – not *keeping up* or *dropping out* highlights the competitive and high stakes nature of *the learning journey*. Conceptual metaphors thus serve to highlight social values: the hovering image conveyed by the metaphor of *helicopter* parents reminds us of contemporary attitudes towards ‘appropriate’ and ‘inappropriate’ levels of parent involvement. And conceptual metaphors shape and constrain thinking (Sfard, 2014); having only a narrow and judgmental set of expressions to explain highly involved parenting behaviours limits how we think about motivations for parent behaviours.

Schmitt (2005) discusses how metaphors can serve as a means of structuring qualitative data and this chapter is structured around the key conceptual metaphors through which each mother describes and interprets her lived experience, and which unify the key themes that emerged from analysis of each mother’s narrative. This analysis identified that each participant used a distinctive organising metaphor to communicate the essence of her experience, and within this conceptual frame, used a cohesive range of metaphors to make sense of and communicate her feelings about her child's learning and social difficulties. These metaphors demonstrated the participants' assumptions around the acquisition of knowledge, or the ways children interact socially, or explained their motivations for being involved in their child's school.

In exploring the underlying meaning of the participants' stories, this chapter responds to the third research question posed in Chapter 1 with the researcher's interpretation of the participants' narratives.

From an ecological systems perspective (Bronfenbrenner, 1977, 1986, 1992), this entailed exploring how each mother described and explained her child's experiences at school: The conceptual metaphors (shown in small capitals) that capture the essence of each mother's experience, and the metaphorical expressions (shown in italics) that each mother used provided insights into how they interpreted their child's interactions in the school microsystem. These included the social environment (interactions with peers, teachers and support staff), the learning environment (interactions with learning materials, pedagogical practices and assessment), and aspects of the broader school environment (school systems and procedures, the built environment).

The metaphors each mother used to describe and explain her own experiences of participating in her child's learning journey provided insights into how the participants perceived and interpreted their own interactions with their child's school and efforts to support their child's education outside school hours.

## 5.2. **Michelle**

Two conceptual metaphors, RELATIONSHIPS ARE CONNECTIONS and BELONGING IS FITTING IN capture the essence of Michelle's experience. Analysis of her narrative revealed a focus on the negative aspects of these concepts and highlighted her strong sense of disconnection and difference from the mainstream experience. This is evident in Michelle's descriptions of Cate's interactions with her peers. It is also there when Michelle described her own relationships with other parents in the school community.

Within this overall conceptual frame, Michelle articulates her experiences and her sense-making activities through five key metaphorical expressions: *fitting in* describes Cate's interactions with her peers; 'a *handful of fog*' describes Michelle's perceptions of school inclusion practices, and Cate's experiences of exclusion; 'parent as *case manager* and reluctant advocate' relates to Michelle's perceived parental role; and 'a different *parenting journey*' explains Michelle's parenting experiences. These metaphors and experiences are explored below.

### 5.2.1. Fitting in

Michelle's narrative reveals that Cate's *learning journey* was affected by her difference from, and rejection by, her peers. Cate's failure to *belong* and her apparent incapacity to *fit in* has been a recurrent source of anxiety for Michelle. Her narrative expressed her attempts to come to terms with the past, what she did not know when Cate was younger, and how this 'not knowing' affected 'things [she] did or didn't do at the time' that might have altered future directions for both mother and daughter. Michelle conveyed the idea that knowing one's child and understanding her needs should be a 'natural' part of the mothering role. Consequently, she found the 'not knowing' very difficult and this became a source of doubt and self-blame:

> [At] first, I just thought, "Oh, she doesn't get along with people. What's going on?" I just, I really just didn't know quite what to do … I really honestly felt, and illogically still feel, that it's somehow something to do with me …

Michelle saw that if her mothering role was to help Cate's social development, then she needed to understand what prevented her from *fitting in*; her narrative demonstrates how Michelle studied and analysed Cate's behaviour, attempting to detect clues about what was emotionally and socially different about her. She saw that Cate could make friends, but she also saw that those friendships did not last. Michelle made sure that Cate *fitted in* at school in terms of her clothes and appearance, but this served to reinforce the invisibility of Cate's difference. Michelle saw that, despite these efforts, Cate was excluded throughout school, in overt and subtle ways: she was invited to few birthday parties or she would hold birthday parties to which nobody came; she would play alongside children but was not invited to join in. At high school Michelle observed that Cate would always get *thrown out* or *phased out* of friendship groups; she felt that the other children had a *radar* for social difference. These metaphors indicate Michelle's own confusion – clearly there was something about Cate, that was invisible to adults, but which adolescents could sense, and which explained their casually cruel and excluding behaviour.

Other than Cate's apparent inability to *connect with* or *get* other children, when Michelle attempted to rationalise Cate's persistent experiences of rejection and exclusion, she found it difficult to articulate or pinpoint exactly what it was about Cate that separated her from the other girls at school:

> She just never got the social cues and social norms of being in a group of anyone, of being a girl. She just never got it. But I can't put it into words what she didn't get …

Earlier in her narrative, Michelle noted Cate's struggle with the conversational give and take that is necessary for friendship, but which is typically difficult for students with ASD. In high school, where 'girls just sit in circles' and interact through conversation rather than activity, this clearly placed Cate at a disadvantage; but the subject of autistic traits and social interaction does not appear to have been the subject of home-school communication.

### 5.2.2. A handful of fog

Michelle's account of Cate's high school years presents a picture of unrelenting and distressing exclusion and victimisation that the school failed to manage, and which diminished Cate both physically and spiritually. Michelle compared Cate's experience with that of her youngest child who has a physical disability and believes that Cate's *invisible disability* had affected her – in terms of anxiety and social isolation – far more than what sees as her sibling's *big disability*.

Michelle interpreted this in terms of attitudes to disability; she reported that at her younger child's school, the other children knew that it is inappropriate to exclude on the basis of physical disability but that the difficulties of neurodiverse girls go undetected. Discussing Cate's teachers' ability to spot subtle exclusion and victimisation in terms of their inability to *cling to* or grasp such an intangible as fog demonstrates the difficulties attending inclusion in schools. Although it was evident that Cate keenly felt her exclusion – Michelle describes her feeling like 'some sort of sub-human creature' – it was easy for teachers to miss the other girls' '*filthy* looks' in the school corridors or at the school gate where Michelle witnessed the other girls whispering about Cate 'as soon as she walked past'.

Michelle reports that Cate's high school made some efforts to support her learning and social-emotional needs and tacitly acknowledged the social difficulties of ASD*;* she was encouraged to see the Learning Support room as a *safe place* at all times. But Cate wanted to be a part of the wider school community and none of this help prevented her from being victimised. Michelle thought that the hardest part for Cate was her level of social awareness; Cate may not have known how to fit in, but she wanted to be included in the friendship groups and was fully aware of her rejection.

Although she acknowledged the school's efforts towards inclusion, Michelle felt that there was too much emphasis placed on Cate's own strategies and social skill development and not enough on enforcing the rhetoric of inclusion. Ultimately, she felt that the school was unsuccessful, and perhaps did not try hard enough, in changing the other girls' attitudes towards neurodiversity; attitudes that Michelle believed came from home. Michelle understood how parents of typical children, who *fit in*, would not *see* the school's culture in the same way as parents of neurodiverse children – they just did not consider the issues of exclusion and rejection unless their own child is affected. So she believes that a school is powerless to create an inclusive culture without changing the attitudes of families within the school community.

### 5.2.3. Parent as case manager

A significant theme in Michelle's narrative is the ongoing and highly involved nature of her parenting role. This is conveyed through the conceptual frame of *'*parent as *case manager*' and identified Michelle's perceived need to micro-manage Cate's journey through school and life, from early childhood through to young adulthood. Michelle described negotiating the health system and questioning Cate's diagnosis; managing the education system to accommodate Cate's needs; mediating professional diagnoses and school learning support; and sourcing post-secondary work, social and study *avenues* for Cate. This theme also conveyed the tension between what Michelle felt 'good' parents should and should not do – 'good parents' should know when to let their child manage on their own. However, Michelle saw that Cate's developmental needs and executive functioning skills demanded her own continued material and emotional support.

Her account illustrates behavioural scaffolding and emotional support that she felt might be judged as developmentally inappropriate by 'typical' parents. She provides the example of birthday parties:

> I'd have to be there because [if] I wasn't… she would end up fighting with the other girls and … getting really upset. I would always have to manage her behaviour.

And noted Cate's developing ability to regulate her own emotions:

> I still have to manage her behaviour… she still finds it extremely difficult …, once she starts getting upset … to calm herself down; I have to help her.

Although Cate's diagnosis eventually contextualised her behaviour and social-emotional needs, Michelle's narrative described how she managed Cate's social interactions while simultaneously trying to understand why Cate could not get along with other children. For Michelle, 'not knowing' meant uncertainty about how to proceed, for example, she moved Cate to different schools and home-schooled her in primary and secondary schools. Michelle also conveyed the sense that she had no choice but to assume the role of Cate's *case manager* since she initially received no advice from Cate's schools. Michelle looked outside the school – to other parents, medical, mental health and allied health professionals, but had 'no *plan in mind*. I had no idea and didn't really understand where I had to go'.

Michelle's story demonstrates how much she would have appreciated coordinated and specific guidance; she gave the impression that her role as Cate's *case manager* was a solitary and unsupported effort which may not have resulted in the best educational outcomes for Cate. It also affected Michelle's own quality of life. Managing Cate's life, looking for a diagnosis that accorded with her parent knowledge, finding the right schooling environment and the right places after school – ensuring that Cate was 'on an *even playing field*' – have all taken a toll on Michelle. She cannot go back to the person she was before her parenting experiences but clearly grieves for the person she might have been.

### 5.2.4. A reluctant advocate

Michelle's narrative conveyed her beliefs about a parent's responsibilities for their child's social-emotional development and wellbeing, but also that schools have a duty of care towards a child when in the school environment. While she assumed the role of *helicopter mother*, it was out of a sense of responsibility to advocate when the school did not appear to be fulfilling their duty of care.

Michelle's interactions with some health and education professionals have been shaped by an absence of trust – her intuitive sense that Cate's issues had been misdiagnosed led her on a *different parenting journey* to find the 'right' paediatrician and the 'right' diagnosis. With the exception of teachers at Cate's Catholic primary school, who scaffolded her social skills and provided her first experiences of success, Michelle's faith in Cate's schools was eroded by their apparent unwillingness or inability to see her difficulties. Michelle knew that Cate was growing increasingly distressed so felt that her teachers should see this too. This came down to a perception that Michelle's concerns about Cate's social and learning progress were being ignored; not feeling believed had a serious impact on her relationship with Cate's school and left her feeling constantly 'frustrated and sad'.

So, a large part of Michelle's perceived role as Cate's *case manager* was to be her advocate in her *schooling journey*. But she was a reluctant advocate – her experiences with trying to communicate her concerns to Cate's teachers left her feeling that she was overstepping some boundary between school and home, and that she was generally unwelcome:

> They made me feel as if I was being *a pain*. Every time *I went up* and said, "Listen, there's a problem". It was almost as if they thought "Oh, this mother is a *helicopter mother* … [she] won't leave us alone".

Michelle's language illustrated a sense of being outside the school: she discussed the challenges of '*coming in* to school', and her reluctance about *'going in* there' and talking to Cate's teachers. She felt that she was somehow interrupting the work of the school. Being uncomfortable with her advocate's role meant that Michelle often wanted to *walk away* from it. Advocating for Cate, managing her social behaviour, looking for a diagnosis that sat with what she knew about her child, and finding the right schooling environment; all of this deeply affected Michelle. She felt *disconnected* from other parents and avoided being involved at school for this reason. However, Michelle felt that without her, Cate would have no representative to make sure she was included and cared for at school:

> I had to, I didn't want to, and that's still how I feel. It's not how I want to be… but when you're a parent who's going to do it? I couldn't … I'd sit there and think, "what if I just withdraw? What if I just let her go?"

### 5.2.5. A different parenting journey

When Michelle described her relationship with other parents, she conveyed a strong sense of not belonging within the parent community and of feeling cut off from the normal parenting experience. As Cate's difficulties meant that her schooling journey had been very different from her peers', Michelle is also acutely aware that she has not had a 'typical *parenting journey*'.

Michelle's narrative suggests that the 'typical' *parenting journey* runs parallel to their child's *schooling journey* and intersects in clearly defined ways – 'typical' parents attend parent-teacher evenings but do not need to advocate for their child. 'Typical' parents might take their child to school but do not need to enter or monitor. For Michelle, being able to '*drop* [Cate] at the front gate' symbolised the school experience that she wanted. It would have meant that Cate belonged in the school environment, that she was not excluded for being different and that she did not need her mother to go where other parents did not:

Michelle's sense of not sharing a 'typical' *parenting journey* has been a source of envy and profound sadness and she is reflective about what her parenting journey might have been like if she'd had a child that *fits in* anywhere. Michelle's sense of disconnect from the wider school community originated with Cate's difficulties in joining peer friendship groups at primary school. Her narrative illustrated how the parent social networks within Cate's school community developed from their children's friendships and those contacts were initiated or reinforced within school spaces, such as serving on the tuckshop or helping at sports days. Michelle's recollection about the birthday party to which Cate was not invited was significant for the way it made her feel excluded from the other parents.

> I just feel like I don't belong. That I don't make those same *connections* that the other parents make with each other

Michelle's sense of otherness from parents at Cate's schools now extends to her other children's schools; she associates the school environment with Cate's exclusion and her own need to advocate for Cate.

Michelle made a clear distinction between 'being involved in schools' as a physical activity of interacting within the school space and with the school community and being engaged in Cate's education. She is more comfortable with home-based learning as it is separate from the school. 'Being involved' forced Michelle to make unfavourable comparisons between her *parenting journey* and other parents' experiences. She felt the scrutiny of other parents whom (she believed) favourably compared their own parenting with her own. She felt that, at some level, other parents look at the parents of children with difficulties and secretly congratulate themselves on doing such a good job. She felt that, for parents who had experienced *a different journey*, online Spaces such as Facebook exacerbated Michelle's sense of not belonging to the mainstream parenting experience.

While she knew, on a rational level, that people 'curate' their lives on social media and that pride in a child's achievements is normal and understandable, broadcasting these triumphs over Facebook served to underline the difference in Cate's educational and life experiences. She knew that parents were not '*shouting* [their child's achievements] *from the rooftops*' to hurt her but it was hard, nevertheless. And it highlighted her own *different journey* apart from the mainstream parenting experience:

As Michelle discussed her sense of present disconnection from other parents, and of grief 'for the things that [Cate] might have been', it was evident that Cate's schooling experiences had a significant impact on Michelle's perception of herself as a parent, her sense of self and the person Michelle had become compared with the person she hoped to be.

> I am a completely different person to what I think that I would have been; and that bothers me...

## 5.3. **Mary**

Two conceptual metaphors, PARENT AS PROJECT MANAGER and PARENT AS ADVOCATE-CHAMPION capture the essence of Mary's experience. Analysis of her narrative revealed a sense of protective responsibility towards Henry. Mary's narrative also revealed a perceptible sense of uneasiness in the school environment, and her comments suggested that being involved in Henry's schooling recalled some of her own more negative school experiences. Mary suggested that her involvement in Henry's school was strongly motivated by her need to communicate and advocate, rather than by any particular desire to be involved in the school community. Within the conceptual frames of PARENT AS PROJECT MANAGER and PARENT AS ADVOCATE-CHAMPION, numerous supporting metaphors depict Mary's experiences; these are explored below.

### 5.3.1. Project manager – supervisor

Mary perceived her primary parenting role as Henry's *project manager,* which she explained via this extended metaphor of construction:

> You're *building a house* and you have all these *subcontractors* … if you *left the job* without any supervision … even though you've given them a …whole set of criteria … you might be disappointed with the outcome.

Mary's responsibilities and mediating activities as *project manager* can be divided into *supervisor* and *communicator* – supervising Henry's holistic development and wellbeing involved co-ordinating and connecting the contexts of home, school and therapy. Mary wanted to communicate a fuller picture of Henry as an individual than the problematic image she felt his teachers had of him.

In her role as *supervisor*, Mary sourced the advice of medical, mental health and allied health professionals, and coordinated appointments, diagnoses and interventions. Mary viewed her role of making things happen for Henry as all-consuming:

> Instead of... doing study or… things for myself, I know that that's my full-time … *number one job*. Managing to *get them through*

Mary saw her engagement in Henry's academic and social-emotional development as a means of developing his wellbeing for, and through education, and as a way to overcome the difficulties of ASD and ADHD. Her goal, expressed through the metaphor of the learning journey, was to help Henry become an independent adult; to help him pass through the portal between childhood and adulthood. This became Mary's main priority, requiring a long-term effort and focus. She realised that this would have a different time frame from parenting a 'typical' child: because of Henry's diagnosis and anxiety, he needed her support and intervention and Mary anticipated that this intensive management role would extend throughout his time at high school. Mary also noted how in her family, although Henry's father is supportive and interested, she has assumed the responsibilities for *managing* Henry's *learning journey*.

Along with the basic, core academic skills which Mary hopes he will master, she was also aware of Henry's need to develop social-emotional skills. She saw this 'holistic approach' as 'wellbeing for education' and suggested that attaining academic skills must be '*built* on a *foundation*' of social-emotional wellbeing. To this end Mary has ensured Henry's access to speech pathologists and occupational therapists, psychological counselling and interpersonal skills programs.

One aspect of her role as *project manager* was organising appointments, supervising intervention programs and communicating all of this with Henry's school. She developed working relationships with clinical professionals and access to these services was made easier by the family's commitment to sourcing private health professionals. For example, a paediatric diagnosis was essential for Henry's ongoing assistance at school and a great deal rides on the diagnosis for Henry (and Mary); one potential consequence of a changed diagnosis was having Henry's disability funding and in-school support withdrawn. Mary observed that private patients have more discretion over choice of paediatrician and shorter wait times, which can be a crucial factor in the context of the school year.

Nevertheless, Mary found the diagnostic process – discussing and reviewing Henry's difficulties and finding a *suitable label* for them – to be an uncomfortable trial. She felt the need to 'prove' Henry's case to the paediatrician and then, even with a diagnosis, she felt she had to prove his needs to the school and that this was detrimental to her relationship with his teachers.

Mary's engagement in Henry's overall wellbeing also underpinned her involvement in his interactions with peers (at school and at home) because friendships and social occasions are complicated by Henry's social and behavioural difficulties and require *scaffolding* and planning beyond what was ordinarily expected for adolescents. Because of previous difficulties at primary school, Mary closely monitored Henry's social interactions and believed that her role of supervisor enabled Henry to develop generally positive friendships. Mary also *pushed* Henry's teachers to report any inappropriate behaviour out of concern that Henry's lack of social-emotional maturity might prevent him from being accepted or *belonging* at school. So, she felt she must ensure that his behaviour does not set him apart.

Mary believed that schools have a role in assisting parents to help their children develop age-appropriate social awareness. She thought that schools should help less socially secure children through explicitly teaching and scaffolding social skill development. Mary acknowledged that high school focuses on subject area skills and content, but she also valued the 'soft' skills – such as cooperative work skills – that will enable Henry to succeed. She reported that the Learning Support teacher was helping him learn to manage his emotional outbursts but, while she recognised the importance of this as a key life skill, she would also like Henry's other teachers help him understand and address the underlying causes of his emotional issues, such as his limited organisational skills. Mary used the metaphor of a *canvas* or artwork for adolescent social-emotional development and viewed high schooling as a time when students do not receive enough structure or explicit guidance to *fill in that canvas* but are left to their own devices.

Mary realised that the social aspects of in-class activities and assessment are very important to Henry's success. A 'good, stable influence' will help him succeed; an easily distracted or disorganised partner will derail Henry's *learning journey*. She felt that, if his teachers do not recognise Henry's inability to manage assessment planning or to work in a group, then it is her parental role to 'catch' him before he *falls through the net* or goes unnoticed by those whom Mary felt should be protecting or helping him.

### 5.3.2. Project manager – communicator

In her role as *communicator* Mary provided Henry's school with what she saw as the criteria for his success. She mediated between home and school, and clinic and school, and continuously sought appropriate avenues of communication with Henry's teachers to share her own experiential parental knowledge, the expertise of clinical professionals, but also to discover what is happening at school. She was generally dissatisfied with the uncoordinated approach to information exchange at his school:

> [We need a] good guideline on how parents, [could] say that they want to meet with the teacher to discuss a few things… parents need to know what their rights are.

Mary believed that parents had the responsibility for initiating communication or 'one-on-one contact' with high school teachers – what she referred to as *getting in teacher spaces* – and thought that regular communication at high school only happened when parents were proactive. She expressed the belief that the nature, frequency and depth of home-school communication in high school is less satisfactory than in primary school for two main reasons: the socio-cultural expectations of independence in high school and the systemic aspects of high school.

Mary acknowledged the socio-cultural expectations of independence in high school: she realised that parents need to gradually let go of their adolescence children and that high schools encourage this. But she also felt that for children who 'cannot function', because of their special needs and their attendant anxiety, achieving independence might take longer than for the typical child. She thought this was exacerbated by the level of assistance given at primary school, but which does not continue to high school; children are *spoon fed* and therefore unprepared for the *big step* between primary and high school.

Within the metaphor of schooling as an on-going story, Mary sees high school as the *next chapter* or stage, but one that is so qualitatively different from primary school as to be incomprehensible or written in *another language*. She thinks that, for both parents and children, the transition to high school is a process of navigating the unfamiliar and there is a significant (and sudden) difference between the expectations around independence in primary school and high school.

Mary stressed the importance of some elements of continuity between primary and high school. For Henry, familiar people who moved between primary and high school (such as an itinerant specialist teacher) acted as points of contact and reassurance during transition. Mary saw this as a process of scaffolding his physical and social-emotional journey from primary to high school and from childhood to adolescence. She saw transition as a gradual withdrawal of support and argued that the time-frame for independence depends on the individual child. She thought that schools should not expect independent behaviours before children are developmentally capable, regardless of chronological age, and should view transition as a process that is adapted to meet individual needs rather than a single period of a few weeks (or a single orientation week). Referencing her experiences with Henry and his older sibling, Mary thought that:

> [for] the well-being of that person, it's a long transitional time from primary school to functioning really well [and] independently on their own.

She felt that to understand the individual child's developmental needs, on-going and two-way communication with parents (as possessors of parental knowledge and expertise) is essential. Mary believed that her experience-informed parent knowledge can help Henry's teachers gain a better understanding of his learning and social-emotional issues, the potential severity of his anxiety, the ways in which it is related to the school setting, and his need for ongoing support. She wanted to help his teachers to understand and manage the triggers that have the potential to cause disruptive and emotional behaviours. She also felt that teachers do not understand how neurodiverse students approach their work and discussed, as an example, perfectionism as an aspect of ASD. When Mary described Henry's refusal to complete an activity in Manual Arts as *shut[ing] up shop*, she described both Henry's behaviour and his emotional state.

Mary identified two main causes of Henry's anxiety: fear of not meeting the school's academic and classroom expectations, and changes in routine around end of term assessment, which he finds very disruptive. She was aware that organisational skills contribute to academic and general success, and that in high school there was an assumption of independent work practices and time management skills. Henry's limited organisational skills and poor working memory are consistent with his diagnosis and are a source of considerable stress for him. Learning how to deconstruct a task and organise it into smaller tasks can be overwhelming and this can then become a source of frustration and anxiety – he wants to meet expectations but does not always know how. Mary wanted teachers to explicitly teach and scaffold independent work practices and effective organisational skills to reduce Henry's stress. In the context of the LEARNING IS A JOURNEY metaphor, preventing *the wheels from falling off* was necessary to help him reach his goals.

It was important for Mary to convey to Henry's teachers that her success criteria for him were different to those she might have for another child. She felt Henry was capable of academic success – with the right support – but did not expect 'As'. However, she stressed the importance of belonging, of allowing neurodiverse students like Henry to have the same opportunities as the other students in the class.

Mary discussed the systemic aspects of high school that make it difficult for teachers to develop personal relationships with students or their parents; and she viewed Henry's IEP as a specific example of these systemic issues. In every school year, no new learning support plan is written until the first IEP meeting, about six weeks into Term 1. Without an IEP, teachers have no way of knowing a student's special needs – unless they review the previous year's plan; and Mary identified times when this did not happen. Consistent with the LEARNING IS A JOURNEY metaphor, Mary feels that, without the guidance of the IEP, students to just *fall in a big void* – they disappear from staff attention and support.

For example, as Henry is disturbed by changes in routine, Mary knew that the end of term assessment blocks presented challenges that would result in emotional outbursts and behavioural issues, which she believed could be handled differently by the school. She found it incomprehensible that Henry's teachers appeared unprepared for this end-of-term behaviour, as all sources of significant stress are identified in Henry's IEP. Throughout our interview, Mary's language, tone and emphasis underline her frustration at not being heard by his teachers and her perception that continuity in care and communication between year levels is lacking. In Mary's opinion, the school's failure to approach changes to routines differently or to scaffold tasks for Henry was a failure to understand his needs and demonstrated systemic inflexibility.

Her efforts to communicate this to Henry's teachers were motivated by concerns that some lack awareness about the purpose of an IEP or, worse, lack conviction about the importance of the IEP for Henry's wellbeing. Mary acknowledged the tension between teachers' enthusiasm to adjust lesson plans, and the realities of the classroom which constrain many teachers' intentions but noted that some disparities between IEP recommendations and staff practices were the result of ingrained attitudes and beliefs towards inclusion. Mary believed that Henry's teachers made individual decisions about implementing the IEP recommendations, seeing it as a discretionary guide rather than *blueprint* for in-class learning support. She felt that it was the number of teachers at high school that expose students to individual interpretations of the IEP and discussed examples of personal attitudes to inclusion that affect teacher practice. In particular, Mary contrasted the values and beliefs of older and younger teachers, noting that younger teachers are more likely to *come on board* and value a more collaborative effort with parents in the *schooling journey*. Other teachers allow personal values and pedagogical judgments to affect how they interpret and use the IEP. Mary had certain expectations around Henry's learning arrangements, so for her, parent-teacher communication (around the IEP recommendations) had become a contentious issue and a rationale for intense involvement in Henry's school.

### 5.3.3. Advocate – champion

Mary viewed a necessary part of her parental role through the metaphor of *Advocate-Champion*. There are two parts to this metaphor: ADVOCACY IS WAR and ADVOCACY IS JUSTICE. As *advocate – champion* Mary understood that within her son's school community, what constituted 'appropriate' parenting behaviours were influenced by ideas of 'good' parenting, and that teachers and other parents might perceive that she was over-involved in Henry's schooling. However, Mary saw this as actively fulfilling her perceived parental role, to fight for Henry's right to be included in the life of the school and ensure he received fair treatment:

> I think you need to be a *helicopter parent* to a certain degree … if you're not *in there*, *making a stand* and being an advocate … your child … won't be included.

Mary viewed the necessity for parental advocacy as an inevitable consequence of limited communication between home and school, and limited school resources or time to devote to students' needs. She perceived that her parental support is crucial in helping Henry to achieve success and her use of martial language such as *taking a stand* and *being confident where you stand* support the metaphor of ADVOCACY IS WAR. Her language suggests that school inclusion practices are not the natural consequence of educational policy, but only result from parents fighting to ensure equal opportunities for their children. At high school, parental advocates for neurodiverse children need to do more than mediate between the systems of home and school; they need to mediate between individual teachers and their child.

In Mary's opinion, the school environment is often unfair towards neurodiverse students, and she found this perceived unfairness towards Henry emotionally difficult. Mary felt that many teachers make assumptions about Henry's behaviour, which they often regard as defiant, disrespectful and non-compliant. However, Mary thought that what they saw as a challenge to their authority might be coming from a very different place. She gave the example of leave passes, which were introduced so Henry could leave the classroom without incident when he feels like he is losing control. However, he is supposed to wait for the teacher to acknowledge that he needs to leave and sometimes he lacks that self-control, so Mary feels like the point of the leave pass is lost.

This is where she felt the need to *step in* and Mary likened her intervention at school to *mak[ing] a stand* for Henry in what she saw as an unequal power relationship between teachers and students. Her view, that children need a supportive adult to ensure a fair hearing of *both sides of the story*, fits within the metaphor of ADVOCACY IS JUSTICE. Although Mary thought that questioning the authority of teachers and going where they are not invited required part of her parental responsibility, she nevertheless saw this as requiring strength and courage.

Mary emphasised the importance of parental information and support groups in educating parents about their child's situation and needs, and in creating a sense of shared parenting experiences. She felt that because parents of neurodiverse children are at risk of loneliness and of becoming *outcasts* who are not accepted by the parents of 'typical' children, their own mental health and wellbeing requires adequate support.

Attending parent education seminars provided by both professional bodies such as SPELD and specific parent support groups, belonging to informal parent groups have all helped Mary to better appreciate her children's issues and needs. She saw this understanding as the basic elements or *building blocks* in sourcing help and becoming a better advocate. Mary believed that these groups provide parents with information and support but also the crucial knowledge that they are not alone, but *in the same boat* with other families experiencing similar issues.

## 5.4. **Frances**

Three conceptual metaphors, MIND IS A MACHINE, MIND IS A CONTAINER and SOLUTIONS ARE ENTITIES capture the essence of Frances's experience. Analysis of Frances' narrative revealed that the MIND IS A MACHINE metaphor allowed Frances to refer to knowledge as an entity. For Forbes, the pursuit of knowledge, and the act of learning was a constant *struggle* and Frances connected what she observed about Forbes' learning difficulties, and the school's response to these difficulties, with his acute anxiety. *Learning is a struggle* is one of three organising metaphors in Frances' narrative. *Falling on deaf ears* sits within the conceptual metaphor of the MIND IS A CONTAINER and represents Frances' perception of her interactions with school professionals and her conviction that much of Forbes' distress could have been avoided if these educators had listened to her expert parent knowledge. *Trying to find answers* sits within the conceptual metaphor of SOLUTIONS ARE ENTITIES and represents Frances' account of her efforts to address Forbes' issues and support his wellbeing her extensive social *networks.*

### 5.4.1. Learning is a struggle

Frances viewed Forbes' academic difficulties and associated anxiety through the conceptual frame of *learning is a struggle* – she could see that acquiring the skills of literacy and numeracy was incredibly difficult for him but also perceived that there was a discrepancy between his learning potential and actual achievement in the classroom.

Frances rationalised the disconnect between Forbes' learning difficulties and her intuitive feeling about his intelligence in terms of being inadequately supported in the classroom and attributed this to pervasive professional misconceptions about

SLDs at his school. She explained that, as far as Forbes was concerned, his teachers may as well have been *speaking an alien language*– he found academic content, skills and processes incomprehensible because of the mainstream approach to explaining basic concepts and communicating expectations.

Forbes held two contrasting views of the school environment: he associated the playground, the basketball courts and the sports fields with success and friendships. However, because success in the mainstream class was measured by mastery of literacy and numeracy skills, the classroom was associated with failure and struggle, and took on the feel of an alien or hostile environment. Frances reported that Forbes felt most secure when he left his class for learning support: 'it was *a safe place* … because … there was *safety in numbers*'. Frances discussed Forbes' diminishing self-esteem, and how his sense of achievement and belonging in the social context of sport and friendships could not override his increasingly negative feelings about learning or translate to a sense of belonging in the classroom.

Frances repeatedly emphasised her perception that Forbes was not inherently anxious; she contrasted his reactions to the classroom environment with the confidence of his interactions with peers, on the sports field and when working on the family farm. She felt that his anxiety was the inevitable consequence of a poor fit between his learning needs and an unsupportive mainstream learning environment: the ongoing effort to achieve in the classroom and the stigma of failing affected the other domains of his life, not the other way around. This was significant for Frances and she was affronted when education and health professionals suggested that Forbes' anxiety could be attributed to parenting or to his personal characteristics.

Frances believed that the teachers at Forbes' schools held generally negative and narrow attitudes towards diversity and disability. She recalled incidences where teachers had been unenthusiastic about offering learning support and sometimes openly dismissive about the possibility that Forbes had Dyslexia. She also described very limited inclusion practices at Forbes' primary school – she commented that the Special Education Unit (SEU) was restricted to 'kids in wheelchairs' and suggested very clear boundaries between the mainstream and Special Education students.

Although Forbes was *pulled out* of class for small group learning support, this was not coordinated through the SEU and Frances discussed her own ongoing conflict with the Head of Special Education (HOSE) around the issue of Forbes' obvious learning issues. She describes very inflexible attitudes towards providing additional support and reported that, for the majority of Forbes' schooling, his teachers did not modify their strategies, learning activities, homework or assessment to meet his needs. She felt that the most effective learning support Forbes received was only towards the end of primary school and as a result of her concerted advocacy efforts.

Frances felt she needed to intervene because she saw how Forbes' learning difficulties were impeding his progress on his *schooling journey*. She described an ongoing cycle of learning interventions that she perceived as insufficient and inconsistent, and that failed to address Forbes' issues. His teachers promised that he would '*just grow wings and ... take off*', but that never happened and six years into his schooling journey 'they were still trying these little things that weren't doing anything … [and] made no difference'. Frances could see that while Forbes progressively *moved up* through the school grades, he remained stationary in his academic achievement. The discrepancy between Forbes' chronological and academic progress meant that he was gradually getting *left behind* his peers and Frances became increasingly doubtful of the school's ability to address his difficulties.

She could see that Forbes also felt the discrepancy. He knew that he was being *left behind* and felt that achieving low grades was synonymous with being stupid and 'dumb'; he keenly felt the stigma of those associations. While Frances had no concerns about Forbes' abilities to make the social transition to high school, academically he was not ready, and this became an increasing source of anxiety 'because he didn't want to be dumb'. Frances reported that Forbes did not want to discuss high school, but she knew about his concern from his distress when high school was mentioned, his social withdrawal and his preference for staying at home.

Frances' story highlights her perception that, because Forbes' educators were either uninterested in, or incapable of finding answers, that responsibility fell to her. She emphasised that teachers need to understand the daily realities for students with learning difficulties and that parents, like her, only intervene to communicate their child's difficulties and distress. She did not perceive herself as generally overprotective and overinvolved in her children's lives and explained that she was comfortable for Forbes to engage in activities that have a level of physical risk and responsibility. However, her experiences appear to have left Frances with an enduring sense that Forbes' primary and early secondary schooling was mishandled by his teachers, learning support staff and members of the school leadership team and she saw that her parental role required her to advocate for Forbes to secure support:

> Criticism of highly involved parents, calling them "helicopter parents" is unfair. My child takes risks – he works on the farm, he rides motorbikes – without "*helicopter parents*"! However, when it is evident that your child is not learning … then you have to start advocating for them... Who else is going to advocate for your child?

### 5.4.2. Falling on deaf ears

Frances' narrative made frequent reference to her repeated attempts to communicate to Forbes' teachers that they saw only a limited a version of his abilities and aptitudes, based on his academic performance, but that this version was not a true reflection of his intelligence:

> I know my child better than anyone … You can tell that he's intelligent … we knew he wasn't dumb.

However, Frances indicated that her concerns were repeatedly dismissed and ignored, and she felt negatively judged, for her persistence, as an overinvolved or *helicopter* parent. Her narrative communicated a sense of unmet expectations and raised two key issues relating to parent-teacher interactions: the importance of respecting and attending to parent expertise and the importance of trust in effective parent-school relationships.

Professional respect for and acknowledgement of parent expertise was extremely important to Frances – the phrase 'I know my child better than anyone' was repeated throughout our conversations – and when she discussed her experiences of being involved with Forbes' school and engaged in his education, she revealed an expectation of reciprocity. Frances expected that her relationship with his teachers and learning support staff would be characterised by mutual respect for parent and professional knowledge, and mutual care and concern for his wellbeing. Instead, her narrative communicates a strong sense of having to *fight* for Forbes' inclusion, and astonishment that her own concerns were being ignored. Frances mentioned several conversations in which both primary and high school teachers dismissed her concerns that Forbes might have Dyslexia. She explained that what upset her most, and what she remembers about her encounters with these teachers, was their lack of respect for her parent knowledge:

> I felt like everything I was saying was just *falling on deaf ears*, like they didn't believe me … they made me feel stupid.

Frances expressed a strong confidence in her parent knowledge of Forbes; that he was not an inherently anxious or unintelligent boy but that his numerous strengths were overshadowed by his struggle with the academic demands of school. Forbes' intelligence seemed paradoxical to her – he appeared to have a strong spatial ability and memory yet Forbes evidently 'couldn't learn like everyone else'. However, Frances also had an instinctive parental sense that 'something was not right' and she expected that his teachers would take a broader view of his difficulties and be open to the possibility of Dyslexia.

Frances reports that she continually requested meetings with the school Principal and HOSE but felt that she did not have an equal voice in the parent-school conversation. She commented on what she saw as the teachers' use of esoteric professional language, or *teacher speak*, as a deliberate means of distancing and disadvantaging her, stating it was 'difficult to *put my arguments* for Forbes *forward*'.

Because she was so frustrated at not being heard, Frances requested a friend with teaching experience to accompany her to those meetings; she became something of a parent advocate who could help Frances to prepare for the meetings and communicate with the school on a more equal basis.

Frances' narrative highlighted the importance of trust in effective parent-school relationships. She entrusted Forbes' school with his academic, social and emotional wellbeing but felt they had betrayed this trust when they *downplayed* his learning issues or failed to provide adequate learning support in the mainstream classroom. Her trust in Forbes' schools was gradually diminished by the perception of being disbelieved or marginalised in the parent-school conversation about his wellbeing; the time it took for the school to introduce appropriate strategies for his learning needs; her repeated efforts to build a collaborative partnership with the school; and comments by education professionals that she perceived as dismissive and derogatory. Her narrative describes adversarial and suspicious interactions, rather than an effective parent-school relationship built on mutual trust.

### 5.4.3. The frustration of trying to find answers

Underpinning Frances' frustration was her awareness of the implications of illiteracy and innumeracy in the 21st century, and her growing and 'desperate' concerns for Forbes' future. She wanted him to be able to participate in the world and flourish fully and independently in his adult life, and her concerns centred on how he could achieve this without literacy skills:

> How do you do a driving a test without being able to read? [H]ow do you get an apprenticeship?

Forbes' transition to high school seems to have highlighted these concerns and Frances described this period as particularly traumatic because he could not participate academically. Aside from the obvious importance of academic competencies for Forbes' future opportunities, Frances emphasised the daily distress caused by academic failure:

> And he would come home crying every day and saying "I'm dumb. I'm the dumbest in the class. I'm so stupid I just want to kill myself".

Frances was motivated by this sense of desperation to *find answers* to Forbes' issues and to provide an opportunity to achieve those adult life skills. She was also motivated by her construction of the parental role – from Frances' perspective, the role of 'parents who care' is to monitor their child's social and academic development. Frances saw Forbes' learning issues as a problem needing to be fixed and that it was her parental responsibility to able to *fix* those problems.

Her concerns raise two issues: the potential financial and personal cost to families in supporting their neurodiverse child, and the ways parents gain access to evidence-based interventions and therapies if they feel unsupported by education and health professionals.

Concerns for Forbes' wellbeing underpinned Frances' decisions around Forbes' schooling and after-school activities relevant to his learning. Her account emphasised the difficulties of being the parent of a neurodiverse child in country towns and revealed the limited options available for rural families unless they have the resources to travel to larger centres. The lack of services corresponds with the inter-dependence of work and home; farming families cannot easily move and change jobs to support their child. Although boarding school is a common option for rural Australian families, decisions around Forbes' high school were influenced by his family's perceptions of his academic and social needs.

However, Frances' account also illustrates her determination to *make things work* despite the distance – her increasing desperation to find the best *fit* for Forbes' learning needs was relative to the distance she was prepared to manage when they found that place.

Frances appears to have lost confidence in conventional therapies due to her experiences with government education, medical and allied health services, and her efforts to *find answers* tended towards less conventional approaches; as she explained, 'you try anything'. Frances' narrative reveals how the limited availability for evidence-based assessment services and long waiting lists make parents vulnerable to less authoritative interventions. She estimates that they would have spent thousands of dollars in different assessments and remedial programs, but that, alongside the financial cost was the cost to their family's cohesion. When Forbes was so distressed at high school, his parents were prepared to do almost anything to help him get through school.

Frances' narrative identified that, because she felt unsupported by education and health professionals, her access to evidence-based interventions and therapies was constrained by what she could discover for herself. She reported how she gained a great deal of support from informal information networks, particularly from other mothers, and that she found out about one of the most effective intervention programs in this way. Frances' social *network* was a complex interconnected system of contacts or friendships with other mothers who had been in the same situation with their own children, and members of her extended social group with professional qualifications who were able to provide advice and information.

Frances' experience demonstrates how schools have an opportunity to provide parents with further information about Neurodevelopmental Disorders. She discussed the lack of guidance from education and health professionals and her efforts indicate how, without professional assistance and guidance, it is not easy for parents to discover what is going on for their child. This was why she valued the information from her informal social support networks and gained considerable support in this manner, particularly from other parents/ mothers and trusted this network to find the answers which were not being supplied by education or health professionals.

## 5.5. **Eileen**

Five conceptual metaphors, MIND IS MACHINE, ANXIETY IS AN ENTITY, PARENT AS ADVOCATE, DIAGNOSIS IS AN ENTITY and SCHOOL IS AN ENTITY capture the essence of Eileen's experience. Analysis of Eileen's narrative revealed a recurring theme of maternal care and nurture. This theme is expressed through the five key organising metaphors that Eileen uses to communicate her experience of Emily's learning journey: *I didn't click* represents Eileen's attempts to understand Emily's learning issues; *anxiety as an iceberg* is the metaphor through which Eileen explains the constant presence of Emily's anxiety; *the painful parent* represents to Eileen's perception of her need to advocate for Emily at school; *diagnosis is a golden key* depicts Eileen's perception of the value of diagnosis; and *the school as family* represents Emily's sense of belonging at school.

### 5.5.1. I didn't click

A dominant theme in Eileen's account of Emily's *schooling journey* was her concern that she did not see the early signs of Emily's developmental issues; and her regret for not having identified the cause of Emily's anxiety at an earlier stage:

> *I didn't click* but looking back those things are probably more meaningful than they were to me then.

Separate incidents that occurred along the way, things teachers, and even complete strangers said all make sense with the benefit of reflection and what Eileen now knows about NVLD. This sense of maternal responsibility is expressed through interrelated metaphors that suggest she was somehow not paying enough attention or trying hard enough. Eileen discusses how she 'didn't *pick up* this anxiety' and identified signs that 'should have *triggered* [her] to anxiety'.

Eileen reports that Emily's learning difficulties were overlooked at school because she was quiet and well-behaved. Her narrative demonstrates how easily a year can elapse with nothing done to address a suspected issue, and how transitions between year levels can be critical stages for sharing information. Eileen indicated that Emily's primary school played a significant role in not identifying or addressing her issues at an earlier stage, and reports a series of missed opportunities and miscommunications: the Grade 1 teacher who was concerned about Emily's lack of progress 'but nothing was ever done or suggested', the Grade 2 teacher who requested assessments but 'nothing was ever done about it, so that was it', and the Grade 3 teacher who let Emily go '*under the radar* all year'.

Eileen felt that the uncoordinated and limited learning support given to Emily at school limited progress on her *learning journey* – 'nothing happened for her'. If Emily's eventual *destination* were to be independence and emotional security, Eileen saw that she would need to help Emily acquire the necessary life skills and competencies. Eileen had ongoing concerns that Emily would not be able to read at a level that would allow her to gain employment or a driver's licence, that is, access the adult world.

Eileen's investment of time and energy into Emily's learning, when she was at primary school, appears to have been both confusing and frustrating – she identified the numerous ways she tried to help Emily, the interventions she tried and how she *craved information* that would help her understand which *buttons [they] weren't pressing.* She discussed Emily's interpersonal skills and emotional intelligence; Eileen emphasised Emily's interpersonal skills and emotional intelligence; feeling that these abilities are not valued at school in comparison to academic success. Eileen felt that there was far more to Emily than her school report card would indicate and that it was a matter of finding the right intervention or program that would uncover her strengths. She commented on how much she valued having access to the right advice and assistance, and how the resources to see private medical and mental health practitioners and allied health therapists had made a significant difference to Emily, getting her *on track* with her learning journey.

### 5.5.2. Anxiety as an iceberg

Throughout her narrative, Eileen returned to the issue of Emily’s anxiety, which she explained through the conceptual frame of *anxiety as an iceberg*. Seemingly, Emily was doing well in her life at school, but there was a depth to her anxiety that was ‘still all there’ and lay beneath ‘*just under the surface*’. Even at the time of interview, when school was not the frightening place it had been, Emily was still made extremely anxious by any disruption to routine, such as anticipating the changes a new school year will bring. This served as a reminder for Eileen about Emily’s underlying anxiety and her own need to remain attentive to Emily’s wellbeing; the ‘tip of the iceberg’ was what people saw of Emily:

> she’s a changed girl… she gets up at quarter to six, she’s got her uniform all out, she makes her own breakfast … she’s all organised.

But Eileen knew that all Emily’s subconscious fears formed the larger part of the ‘iceberg’, beneath the surface and, with this knowledge, Eileen realised that she must remain alert to Emily’s wellbeing.

The subject of Emily’s regular ‘horrendous nightmares’ and night terrors was a repeated theme in Eileen’s narrative, and they became a distressing and insoluble problem for her family. These episodes appear to have been deeply disturbing for Eileen, and they must have been exhausting, Emily experienced night terrors every night, often twice a night. And as Emily would always express her fears about school during these episodes, Eileen was concerned about how *the pressure of life* was so evidently *weighing heavily* on Emily’s mind. Eileen saw that calming Emily and caring for her was part of her maternal role. It was ‘just such a mothering thing’, to lift off the pressure of Emily’s anxiety.

Emily’s fear of school runs through Eileen’s narrative – the quite normal anxiety that children experience about academic performance or failure, being in trouble or criticised were amplified and had a pervasive and negative impact on Emily’s life and attitude to school. Eileen reported that throughout primary school, Emily continually felt unwell and was reluctant to go to school. Being unable to complete her schoolwork or homework, and being in trouble for that, was a constant source of anxiety. This was prompted by the sound of the clock ticking on the *60 Minutes* current affairs show; signalling the end of the weekend and the start of the school week. For Eileen, the fact they could ‘get through *60 Minutes* without tears’ was symbolic of Emily’s improved wellbeing.

Eileen understood the importance of recognising the signs and symptoms of anxiety so that children’s fears do not affect their day to day life or prevent them from enjoying things that their peers enjoy. Although she had friends and was normally quite gregarious, Emily missed out on important social events during her childhood because of her anxiety and fear of the unknown – how she would manage the games at a primary school birthday party; how she would manage a high school dance.

Eileen was advised that anxiety is a component of NVLD and Emily’s inability to make sense of the school environment is a contributing factor. The paediatrician advised Eileen that limiting Emily’s anxiety and managing her mental health and wellbeing was a priority, over and above concerns about academic achievement. His advice highlights the importance of mental health and wellbeing to the *schooling journey*, and the necessity of education to help students understand their mental health and make good lifestyle decisions.

### 5.5.3. The painful parent

For Eileen, an important component of maternal care was advocating for Emily at school. There were two clear phases to this role: the primary school years when Eileen seemed to be ‘constantly *up at the school*’; and Emily’s recent years at high school, when Eileen had more confidence that Emily could manage on her own.

Emily is the youngest child in a large family and Eileen had become accustomed to an ‘invitation only’ role in the parent-school relationship; her narrative demonstrated quite conventional ideas about acceptable levels of parent involvement. Her repeated use of the phrase *going up to school* indicated that she was comfortable with the idea of being invited to parent days or to volunteer at the school but not with the idea of being involved in the teachers’ professional world. Although her other children had attended the same school, Eileen had not felt that she needed to intervene in their schooling or to advocate for them as she did for Emily. She felt that she was constantly *up at the school* because it was her responsibility to explain why Emily had been unable to complete her homework and to convey the distress Emily felt: ‘you’re always *up there* saying “this is why it’s not done”’.

Eileen's narrative conveyed a sense that she had perhaps trusted the school too much when Emily was younger and that, had she pushed harder in primary school, Emily could have been diagnosed earlier. Although Eileen was clearly uncomfortable in her role as Emily's advocate, her priority was Emily's wellbeing, which far exceeded her own beliefs about appropriate parental involvement in school:

> You've just got to be the advocate for your child, and you want to be but, dear, you feel … that *painful parent*.

With Emily in high school, Eileen still perceived that there was a stigma attached to being overinvolved but saw a continued need to represent and protect Emily's interests. She felt that there was a communication gap between home and school and that schools do not always hear or understand what parents are trying to tell them; so being repetitive or *painful* helps parents to get their message across (the parent-school barrier) that their child is unhappy, is not flourishing and needs help. She considered that the structures and systems of high school contributed to this communication gap and trying to convey this message to all Emily's teachers meant that there was a there was a strong probability that important information would *get lost in translation*.

Eileen did not want parent-school communication to be a major undertaking – she might have wished to pass on a minor concern or had a brief question – but felt that allowing parents to contact the school in this way helped to prevent major issues from occurring and built trust. She also made an important point about parent inclusion in the school community, suggesting that parents needed to feel comfortable approaching teachers and not as though they were intruding or interfering. While Eileen understood the need for boundaries between parents and teachers, she suggested that protocols to inform parent-school communication were necessary but missing.

### 5.5.4. Diagnosis is a golden key

> [An official diagnosis is] *a golden key*; you get noticed and you get listened to … if you go to a school and say, 'the paediatrician said,' all of a sudden, you can sort of *cross barriers* that you can't always as a parent.

The metaphors Eileen used to describe the paediatrician's diagnosis and her perception of the parent-school relationship, are coherent with the metaphor of the SCHOOL IS A FORTRESS (Henderson, Mapp, Johnson & Davies, 2007). In this conceptual frame, educators can be seen as the ‘gatekeepers’ who will admit other authorised persons, such as medical professionals but who deny parents access. Conceptualising diagnosis as *a golden key* indicated that Eileen reasoned about this authority in the same way that we reason about keys – they open doors and allow access.

Although Eileen’s account of Emily’s high school was generally positive, at first she felt at a disadvantage in the parent-school relationship. Eileen gave an example of where her parent knowledge coincided with professional knowledge but had carried no authority: she had felt negatively about Emily’s homework since primary school, seeing it as a significant and pointless source of anxiety, pointless because Emily could rarely finish it on her own. But, she stated, ‘teachers are *programmed* to give homework’. Her concerns were only taken seriously after Emily’s diagnosis and the paediatrician’s own opinions about the practicality of homework were made known to the school.

Eileen was not initially certain that visiting a paediatrician was the right *avenue* for Emily’s issues; she reported a perception that paediatricians only look after physically unwell children and did not feel that Emily’s night terrors were sufficiently important to warrant a visit. Discovering that developmental paediatricians deal with exactly the type of issues which Emily was experiencing was a turning point that could have perhaps occurred earlier with the right professional advice from the school.

Eileen recalled Emily’s diagnosis as starting with her own concerns about her anxiety. This led her to visit the Learning Support teacher who then referred Emily to the school counsellor. Emily was finally diagnosed four years after her initial assessment. This illustrates a number of things – first, the chain of referral in schools from classroom teacher to learning support to guidance officer/ school counsellor can present one type of *barrier* to parents. As in Eileen’s case, parent concerns can initiate this process, but they have to be heard first, that is, their concerns have to receive the attention of an education professional.

This anecdote also illustrates that the diagnostic process requires that parents have confidence in their capacity to advocate, and that they are tenacious there is potential for delays at all stages, depriving the child of important support at a developmentally crucial time of their life and education. It was only once Emily received a diagnosis that she could have an IEP, and it was only then, that Eileen felt communication between school and home was formalised and improved.

Talking of Emily's diagnosis was highly emotional for Eileen and her narrative illustrated that, for a parent, an accurate diagnosis evokes mixed emotions: there was relief at having a diagnosis that answered long-standing questions about Emily's difficulties and anxieties. On the other hand, Eileen was dismayed by the seriousness and far-reaching consequences of that diagnosis, which was illustrated by the paediatrician's descriptions of the serious implications of NVLD. According to the paediatrician, Emily's peers would *soar*, whereas Emily would *trail along behind her classmates* until she reached *a plateau* around Grade 6. While the diagnosis clarified Emily's difficulties at school, it also placed distressing limits on her *learning journey* and life outcomes.

Eileen reported that she and the school were united in focusing on Emily's social-emotional health and wellbeing. She believed that this sense of equality in the parent-school relationship partially derived from her long-standing experience as part of the school community. But she also felt that the *golden key* provided by the paediatric diagnosis conferred on her a new level of authority and sense of partnership– she regularly used 'we', not 'I' and 'they' when discussing joint parent-school decisions around Emily's wellbeing.

### 5.5.5. The school is a family

Eileen's sense of maternal care and responsibility for Emily's wellbeing, and the importance she placed on family extended to Eileen's perceptions of Emily's education. When Eileen spoke most positively about Emily's school, it was in terms of the SCHOOL IS A FAMILY metaphor. Eileen expressed this central maternal concern over Emily's wellbeing when describing her search for *nurturing* environments for Emily; through her anxiety about how far to *push* Emily away from her maternal protection; through her desire to *lift off* the pressure of Emily's anxiety and through her reassurance that, in the future, there will always be someone to *watch over* Emily.

For example, when Eileen wanted Emily to try a season of netball, she believed this was a potentially positive experience; many children find their ‘place’ in a team and their strength in sport. Eileen wanted Emily to experience the potential fun of playing a sport as well as the camaraderie and close friendship of being in a team – she knew that this very *nurturing* and supportive group would help Emily (even if she only went for the ice block at the end!). She illustrated, with the metaphor of *pushing* Emily to participate, the balance parents must find between encouragement and coercion.

Decisions around high school for Emily were influenced by the family’s previous experience with a Catholic girls’ school. Eileen felt that the school was caring, and this tallied with the paediatrician’s recommendations to ‘go somewhere that is very *nurturing*’ with a ‘broad curriculum’. Eileen makes the point that parents’ perceptions of ‘necessary’ skill sets may not *mesh* with educators’ and that parents of neurodiverse children may prioritise ‘life skills’ over the *push* for academic achievement. Eileen valued a caring school environment, where staff were concerned with Emily’s holistic wellbeing and understood the significance of academic pressure on her anxiety.

Eileen had a number of hopes and concerns about practical aspects of Emily’s future, such as getting a job and learning to drive. These were goals Emily must achieve – future *roads to cross* on her way to independence and adulthood. But she was secure in the knowledge that, being part of a close immediate family and large extended family, there would be a place where people who care for Emily would be *looking out*, *watching over* and taking an interest in her wellbeing.

Eileen’s sense of maternal obligation to nurture Emily extended to her expectations that Emily’s school had a moral obligation to demonstrate a similar degree of empathy and care. Eileen’s use of *nurturing* and *caring* to describe Emily’s school throughout her narrative suggests that she believed aspects of Emily’s school community, such as the Learning Support unit, shared the close supportive aspects of a biological family. It was important to Eileen that Emily felt that she belonged with the girls and teachers in the *Learning Support family.*

What this meant, in practical terms was that, at the time of the interview, Emily had become sufficiently comfortable with her place in the *learning support family* that she could advocate for herself. Eileen welcomed this and saw that being able to express her concerns independently was an indication of her emotional security and maturity. Eileen expressed the belief that the effective learning support which Emily received had relieved much of her anxiety relating to school and, generally, she was also comfortable with ‘not working *on the same level*’ as the other students in her mainstream classes. However, it was also important to Emily that she *fit in* with other girls in the mainstream classroom and wanted her learning support and modifications to be unobtrusive. Eileen felt that clear and consistent communication between staff and the learning support teacher contributed to a coordinated effort among the school professional staff to care for Emily’s wellbeing. Emily’s newly developed confidence at school enabled Eileen to take a less involved role in her schooling.

## 5.6. **Eloise**

The theme of distance dominated Eloise’s narrative, and this was expressed through the conceptual metaphors of DISTANCE IS AN ENTITY and SUPERVISION AS OBJECT. *Managing distance* represents Eloise’s primary responsibility for organising and managing Rory’s diagnosis and therapy. Distance from regional centres added a layer of complexity to this role. *Keeping an eye on things* represents Eloise’s need to manage and supervise Rory’s educational contexts, with the added complication of distance. As a response to her situation, Eloise *built* trusting relationships with medical, allied health and education professionals as means of *bridging* the cultural and geographical distance between the family property in rural Queensland and Rory’s urban school environment.

### 5.6.1. Managing distance

This aspect of Eloise’s account centred on the difficulties associated with supporting and educating a neurodiverse child in a remote rural setting.

For Eloise, overcoming the physical distance between the family property and suitable schools and services became a dominant theme in her parenting experience. The conceptual frame of *managing distance* illustrated some of the inequalities that exist between urban and rural families in accessing quality education and therapeutic services and Eloise's account revealed several examples of how reduced access to medical, mental health and allied health professionals and services impacted the family. For example, the government speech pathologist, occupational therapist and school Guidance Officer all worked on a rotational basis and were based in the nearest regional centre, hundreds of kilometres away. Eloise commented that Rory rarely saw the same person and they only visited once a semester; her story illustrated how Rory's *learning journey* was *disrupted* by these issues of continuity and limited access to assessments, interventions and remedial therapies. Eloise assumed the role of *parent as co-therapist* out of necessity, and although the other participants reported a similar responsibility for their child's follow-up exercises and therapies, Eloise's account demonstrates the way distance adds to the burden of families of children with disabilities.

Eloise's narrative also illustrated how distance became an additional factor in the *burden* of maternal care. She *measured* distance in time from home as often as she *measured* it in kilometres because of the impact that travel had on her daily life – she *measured* the distance from home to the closest regional centre in terms of the one and a half hour's drive it took to see the occupational therapist. She *measured* her commitment to encouraging Rory's sport – this was his strength and it contributed to his wellbeing – in terms of the '7-hour round trip for a game of footy'. One of the difficulties that Eloise identified with her role of *parent as co-therapist* was finding the time to do Rory's remedial exercises *on top of* school work and in after-school hours. When Rory was diagnosed with Dyslexia, he began two remedial programs and, because the developmental paediatric group was based nearly 700km away, Eloise supervised the programs, tested Rory, had weekly teleconferences with the educational psychologist and provided reports based on weekly targets and test results. And *on top of* caring for their other children and helping to run their property, Eloise drove the daily 100km return trip to school, which took several hours of each day. Although she believed that this effort made a difference, and she enjoyed the sense of being in a collaborative partnership for Rory's benefit, the *cumbersome* workload became overwhelming and *took a toll* on her quality of life. Apart from expressing concerns that she was not properly trained to manage Rory's therapies, she reported that by the time he went to high school she was:

> completely exhausted. [I thought] “At some point, very soon I need to *pass this on* to people who are trained to do this.”

Eloise’ story also illustrated that access to reputable services depends on parents’ ability to discover them, that is, having a sufficiently broad social *network* or support from school professionals (both in this case) and being able to commit personal and financial resources to supporting their child. She estimated that they spent thousands of dollars on diagnoses and remediation programs, not to mention the travel costs involved in visits to Brisbane.

### 5.6.2. Keeping an eye on things

This aspect of Eloise’s account centred on her reported need to manage and supervise Rory’s educational contexts, and the impact of distance on her ability to be involved in Rory’s school. Her narrative illustrates the types of questions rural families face about how best to educate their children and balance family and work, when factoring in distance from schools and professional services. Eloise narrative illustrates how these decisions are complicated by the necessity of balancing the complex needs of neurodiverse children against the family’s needs in general.

In managing Rory’s schooling, Eloise’s goal was to ensure a *balance* between Rory’s wellbeing and the pressure to succeed at school. This *balance* represented concerns that Eloise has had around Rory’s immediate academic difficulties and anxieties, and her projected concerns about where he might eventually *fit* within a changing world. She knew that the future skills he might need to flourish as an adult in the 21st century would depend on a degree of academic competency.

Eloise’s efforts to support Rory’s learning throughout primary and early secondary school were orientated towards *getting him to a point* where he could be independent. At the time of the interview, she felt confident that Rory was progressing at school. The next step would be to help set him up for his adult life; she hoped that the vocational education pathway he planned to take would allow him to pursue a trade qualification. At the same time, Eloise’s main concern was that he finished school without being *completely scarred* by the whole experience. While Rory’s current school offered many opportunities for him to enjoy an extensive social *network* and excel in sport, it was a highly competitive environment and

Eloise was aware of the significant long-term effects of learning difficulties and the *pressure* of expectations to *keep up*.

From early primary school, Eloise's interactions with education professionals were determined by her perception of their attitudes to Rory's Dyslexia and their concerns for his wellbeing. This was illustrated through her account of clashing with Rory's new Principal over the terms of his IEP. Eloise felt that by rejecting the IEP recommendations, the Principal not only trivialised Rory's learning needs, but undermined the collaborative partnership Eloise felt she had built with previous staff:

> It made me feel completely *out of control* of the whole situation and furious … And it got to the stage of 'what do we do?'

Eloise's emotional reaction was understandable; the IEP signified that Rory's learning issues were recognised and validated; and provided the continuity in his education that had been lacking. Significantly, as its recommendations aimed to minimise Rory's anxieties around his learning difficulties, it relieved some of Eloise's concerns for his wellbeing. Her response to this impasse illustrated her confidence in the P and C as a source of advocacy support. Eloise's account finding the *right way to go* in making a complaint to the education authority, and the result of that complaint, exemplified how she felt that *finding the right people*, and the right information enabled her to manage Rory's *learning journey*.

Eloise discussed Rory's Grade 5 teaching Principal in a completely contrasting manner – this was someone whom she felt had a positive and accepting attitude towards Rory's difficulties. Not only did he recognise Rory's strengths and recommend an educational psychologist, but Eloise felt that this was a partnership built around supporting Rory and his family.

The decisions around Rory's transition to high school related to Eloise's awareness that she needed to *let him go* – but that he needed her continued support. Although Rory was always going to move away to boarding school at some point, Eloise felt he needed to be *eased into* the type of independence this required. She emphasised her belief that Rory needed *a stepping stone* between his small rural primary school and boarding school, that would help him gradually adjust to a larger, more impersonal school with all the social-emotional challenges inherent with being 700km from home.

Eloise explained that moving schools for Year 7 was a difficult decision, particularly as Years 5 and 6 were ‘fabulous years’, during which Rory’s confidence grew, and his strengths were celebrated. She saw there were advantages to Rory being at a small primary school in terms of teacher-learner ratios and access to learning support but there were perceived disadvantages to being the only child in his Year, which concerned Eloise on a number of levels: first, she thought his learning difficulties were becoming more obvious; while she did not discuss her concerns with other parents at the school, she was aware that they would have known about Rory’s difficulties. A strong motivator for the move to a larger school was her desire to protect him from these feelings of isolation and scrutiny.

Eloise also felt that Rory had become dependent on teacher aide support, so that he lacked the skills to work and problem-solve independently. Decisions around high school were informed by these concerns and part of the rationale in accompanying Rory to his new school in Regional City was to *wean Rory off* this assistance, while conveying the message to his teachers that he still needed *support behind him*.

While several factors influenced the decisions about where to go, the most important to Eloise was her perception that their eventual choice was a *gentle school* with a *nurturing* environment. She felt Rory needed a *softer, gentler* approach so he could develop independence while still having Eloise’s support and supervision.

Eloise saw herself as Rory’s *support network* and her parenting as a form of practical and emotional *scaffolding*: gradually withdrawing her guidance would help Rory develop social competence and coping abilities. She felt that removing that support too quickly would have destroyed Rory’s confidence in his own abilities; she felt ‘he would have c*rumbled*’. Eloise wanted to have the type of relationship with Rory’s school that allowed for her ongoing support; she acknowledged that, for Rory, ‘*finding his feet* socially and emotionally’ and becoming independent was a necessary aspect of his adolescent development but not at the cost of his personal wellbeing.

A key aspect of Eloise's supervisory role was her perceived need to manage Rory's school environment by proxy. Her narrative indicated that Rory's journey through high school had been, to date, uncomplicated: *smooth sailing*. This was a relief for Eloise who had been so anxious about Rory and his future for so many years. She was still concerned that she should be more actively involved – for Eloise, being *on top of things* had been her default position in the parent-school relationship. However, she managed from a distance and had to hand over the direct supervision of Rory's schooling:

> [I have stepped back] but I had to make sure that there were people there taking over from me as well… [but] I'm still very much … *keeping my finger on it*.

Through the strategy of developing a close acquaintance with the Head of Middle School, Eloise had a personal parental representative in the school. Her language choices indicated an emphasis on retaining a degree of parental supervision, something Eloise could not *manage* at a geographical distance, where Rory was physically inaccessible to her. She needed a proxy parent, to take an interest in Rory's wellbeing and respond to any situation that might arise.

Nevertheless, Eloise was generally confident that Rory was getting adequate support, academic assistance and assessment planning, to remove the need for her own constant vigilance. Eloise acknowledged that her efforts to advocate for Rory could be construed as over-involvement, but she emphasised that it was her parental responsibility to ensure that he had the best chances for academic success and social-emotional wellbeing. She was also aware of the negative connotations attached to being a *helicopter mother*, that is, over-involved and over-protective, but this did not mean she would not have advocated for Rory. She felt that he would not have succeeded 'on his own without intervention'.

Eloise's narrative discussed Rory's sense of security, and anxiety in terms of his sense of belonging within the social context of the school environment. Rory's strengths – his sporting abilities, social skills, good looks – all contributed to social status which gave Rory a sense of belonging among his peers at school. However, these strengths also allowed Rory to *slip through the cracks*; Eloise felt that Rory's learning difficulties went unnoticed by teachers because of his other, compensatory, strengths. Because he was so conscious of the stigma attached to his learning difficulties, Eloise felt that Rory used this situation to his advantage.

For Rory, inclusion meant having the right type of learning support without *standing out* from his peers. His anxiety was strongly related to a sense of difference and Eloise reflected on how her concern for Rory's academic progress influenced past decisions that might have unintentionally exacerbated this anxiety. For example, she considered withdrawing Rory from the Year 9 NAPLAN test as she knew that it would be challenging and stressful. However, Rory's main concern was that *not* participating would draw more attention to his learning issues – exclusion from the test was exclusion from the group. Peer tutoring, which Eloise actively encouraged, also highlighted his learning issues – he did not want his friends and classmates to *pick up* how much he *struggled* with reading. Eloise summed this up when she stated that Rory's fear was for his friends to query why he was not '*in here* with us'.

## 5.7. **Conclusion**

This chapter explored how each mother's narrative illustrated what it was like for her child in school learning and social environments. The narratives also described what it was like for the participants, as parents of neurodiverse children. They talked of supporting their child's learning journey; mediating the worlds of home, school and clinic; and advocating for their right to participate at school.

Exploration of the key conceptual metaphors that structured each mother's thinking about her experiences, and the metaphorical expressions through which each mother articulated that thinking, provided a window into their perceptions and interpretations of their child's experiences at school and their own experiences of the parent-school relationship. Although some mothers used a richer and more idiosyncratic array of metaphors to communicate their experiences, all conveyed the complexity of parent involvement and the difficulties of trying to understand their child's needs while conceptualising her child's and her own experiences.

Present within each mothers' narrative, familiar and established metaphorical expressions described similar experiences shared by their children, similar situations within their children's schools and similar patterns of teacher response to their children's difficulties. Each mother told the story of managing her child's learning journey; of her own efforts to find answers that explained her child's issues; of her determination to take a stand and advocate for her child; and of the stigma attached to being seen as a helicopter mother. In other cases, these mothers described similar situations but conveyed a very individual emotional response through their use of metaphor. Where one parent viewed parent networks as a source of support, another might have seen them as a symbol of her disconnection.

Chapter 6 explores these instances of similarity and difference, across the participants' narratives, and engages with the research literature to help explain the mothers' shared experiences.

# CHAPTER 6: THE PARTICIPANTS' COLLECTIVE NARRATIVES

## 6.1. Introduction

In Chapter 4, the participants' narratives communicated their perceptions of what it is like to parent a neurodiverse child, and how they made sense of their child's educational experiences. Chapter 5 responded to Reissman's (2005) assertion that narratives 'do not speak for themselves' (p.2) by attempting to explain the participants' experiences and motivations. It did so by identifying and interpreting the conceptual metaphors through which each mother revealed her lived experience, and which were embedded in the text of her narrative. This Chapter unpacks the metaphors identified in Chapter 5 and represents a deeper layer of phenomenological analysis – the combined essence of these mothers' experiences and the second stage of the double-hermeneutic of phenomenology.

IPA's chief concern is with the idiographic – the meaning attached to 'a particular thing, for a particular person, within a particular context (Smith, 2019, p. 169). To this extent, the participants' individual personal narratives have value in their ability to impose order on, and make sense of, their lived experience, and enable others to gain perspective of their own histories. However, as Bruner (2004) suggests, a more intense 'narrative power' can be achieved through combining narratives that 'spring from a common landscape' (p.702). This chapter demonstrates the strength of the participants' collective narratives and, through these, their shared experience.

Bruner (1991) identifies the practical question about how, when faced with a set of individual personal narratives, we 'cobble stories together to make them into a whole of some sort' (p.18). At the most practical level, IPA responds to this challenge through clustering the participants' experiences into convergent and divergent themes. In part, therefore, this chapter is the product of a thematic analysis across the participants' narratives.

Bruner (1991) also discusses the phenomenon of 'narrative accrual', the coherent stories that emerge within families and ethnic groups and that amount to a shared 'culture' or 'history' (p.18). The stories that the participants told shared an emotional congruence – fears for their children’s present, hopes for their futures, and an overwhelmingly protective sense of responsibility. This went beyond the common thematic threads that bound their children’s interactions within the school’s academic and social environments and their own interactions with educators. From the perspective of ‘cobbling’ together the participants’ narratives, finding this common ‘emotional essence’ of their experiences was a more intuitive act, aided by the incidence of conceptual metaphors. When analysing for themes common to the participants’ narratives, these emerged as a series of metaphor ‘families’. The overarching metaphor ‘families’ share a conceptual similarity: they demonstrate the mothers’ metaphoric thinking around, and feelings about, their children’s experiences in mainstream school environments and their own parenting experiences.

When the participants talked about their concerns and their experiences, a series of thematically and emotionally coherent narratives emerged from the process of grouping their metaphors of lived experience. This chapter presents three ‘accrued’, or collective and overlapping, narratives, organised around three metaphor ‘families’ that communicate the participants’ collective voice. Each is represented by a single participants’ metaphor that was selected to capture the essence of the mothers’ shared experiences:

*Figure 6.1* The participants’ collective narratives

These narratives demonstrate how the participants’ reasoning about journeys, gateways, and communication, is mapped on to their reasoning about their child’s academic and social development, their own parental role, and their relationship with their child’s educators. The three overarching metaphors are contained within the overlapping circles of Figure 6.1. and demonstrate both the interconnectedness of the participants’ experiences of *being-in-the-world*, and the “tantalizing and elusive” nature of capturing and representing lived experience (Smith et al., 2009, p. 33). IPA does not aim to reduce experience to a single essential theme, and the triad depicted here illustrates the complexity of the mothers’ lived experiences.

Secondary narratives contribute to, and sit within, the collective narratives. These are organised around coherent metaphors of lived experience that best represent the participants’ shared experiences of subsidiary phenomena. Visual metaphors reinforce the verbal metaphors, provide a graphic link to each contributing narrative and encourage insight into the participants’ lived experiences. Each collective narrative corresponds to a circular graphic that is emblematic of the whole; where appropriate, the segments are emblematic of the parts. These visual and verbal metaphors are repeated throughout Chapter 6, serving three purposes: (1) to support and reinforce the participants’ metaphors as a visual expression of the participants’ metaphoric thinking (El Refaie, 2003); (2) as the graphic representation of the ‘metaphor families’, the combined narratives, the participants’ shared experiences of three central phenomena – the phenomenon of concern for their child’s academic and social development , the phenomenon of parental caring, and the phenomenon of relating to their child’s educators; and (3) to illustrate the whole-part-whole relationship of the hermeneutic circle and to reinforce the message of what it was like, for these participants, in this context (Smith et al., 2009).

Within the contributing narratives, common aspects of the participants’ lived experiences are expressed through metaphors derived from the text of their narratives. These are italicised and emphasised in colour; examples are highlighted and are included, in full, in Appendices 13 and 14.

**Collective Narrative One**: The conceptual metaphor of LEARNING IS A JOURNEY provides a way to understand how knowledge and skills accumulate in a typically progressive manner. The participants’ explanations of their children’s experiences at school, and the impact of the school environment on their wellbeing were consistent with aspects of this conceptual frame and gave rise to the collective narrative of *The Learning Journey*. The metaphorical expressions that fit within the metaphor family of *The Learning Journey* represent the participants' understanding of their children's educational progress and stasis, success and failure.

Two secondary narratives contribute to *The Learning Journey*: the first tells of the participants' concerns for their children's current wellbeing and is represented by Eileen's metaphor of *fish out of water*. The second tells of the participants' concerns for their children's future wellbecoming and is represented by the metaphor of *future proofing*, a metaphoric phrase used by several participants that conveys their common worry about their child's journey into adulthood and beyond the security of family life.

**Collective Narrative Two**: The conceptual metaphor of PARENTS ARE PROTECTORS provides a way to understand aspects of the parenting role. The participants' explanations of their role in their children's uncertain learning and schooling journeys gave rise to the collective narrative of *Helping Them Get to the Other Side*. The metaphorical expressions that fit within this metaphor family represent the way each participant rationalised her parental role – as supporter, manager, supervisor and advocate. These mothers perceived inherent risks, in the mainstream school environment, to the wellbeing of neurodiverse children, so assumed these roles as a means of safeguarding their children.

There are four contributing narratives: The first, *lifting the pressure* explains the mothers' perceived mothering responsibilities and is represented by a metaphor from Eileen's narrative. The second explains the participants' efforts to support their child's learning journey and is represented by Michelle's metaphor of *case managers*. The third explains the mothers' supervision of their child's schooling journey and is represented by Eloise's metaphor of *keeping a finger on it*. The fourth explains their perceived responsibility to advocate for their child in the school environment and is represented by the shared metaphor of *taking a stand*.

**Collective Narrative Three**: The conceptual metaphor of MIND IS A CONTAINER provides a way to understand barriers to communication between parents and educators. As a clearly bounded space, the container can be impervious to external input, such as ideas or thoughts, and some effort is required for this transference. The conceptual metaphor of SCHOOL AS FORTRESS provides a way to understand barriers to participation and how the participants felt ‘outside’ the school.

The participants suggested several barriers to effective parent-school partnerships that they felt were put in place by schools. The most significant revolved issues of communication and are explained through the collective narrative of *Falling on deaf ears*. The overarching metaphor that gives its name to this collective narrative is from Frances’ narrative and conveys her perception of the way schools (do not) attend to parent concerns.

Chapter 6 explores these collective narratives, identifying the thematically and emotionally congruent aspects of these mothers’ lived experience. This chapter also contextualises the collective narratives within current research relating to disability and inclusion, and within the broader social ecologies of contemporary parenting and what it means to be ‘good’ mothers. Finally, this chapter outlines a number of underlying principles relating to school learning and social environments and parent-school relationships that were drawn from the participants’ shared narratives.

## 6.2. **Collective Narrative One: The Learning Journey**

Each mother described her child's cognitive and social development through metaphors that highlighted the negative aspects of the conceptual frame of LEARNING IS A JOURNEY (Turner, 1998) and explained her child's different developmental trajectory as 'not a typical *learning journey*'. The participants described their children's progress through school through the conceptual frame of SCHOOLING IS A JOURNEY and used metaphors consistent with LEARNING AS ACQUISITION (Sfard, 2014), MIND AS MACHINE (Lakoff & Johnson, 1999), and THE SCHOOL AS A FACTORY (Schlechty & Joslin, 1984) to make sense of their children's inability to 'acquire' the knowledge, processes and skills expected for their developmental ages and stages. Each of these complex metaphors projects a different set of images but shares a mechanistic conception of learning, schools and education in which knowledge is construed as parts in a machine that *click* into place; or as a commodity which is added to and stored. When this process went awry, these mothers described how their child 'just never *got* books' or 'didn't *get*' the times tables or spelling, and they viewed this as a 'problem' that could be *fixed* with the right type of instruction or intervention. Michelle also used this conceptual frame to explain Cate's difficulties in understanding social rules as an inability to '*connect with* other children'. Paradoxically, although the participants discussed the importance of whole-school acceptance of difference and shared a 'person first, disability second' perspective, *fixing* their child's learning, social-emotional or behavioural 'problems' became a key objective. When Eileen stated that there must have been *buttons we weren't pressing* to somehow 'unlock' Emily's learning potential, she was expressing a sense of responsibility that was common to the participants.

Staying *on track* in the *schooling journey* referred to the participants' expectations around academic progress and measurable age and stage related milestones. However, their children's learning, social-emotional and behavioural difficulties presented as obstacles that caused them to go *off-track*, to *trail along*, or to *fall behind* their peers. Because of these obstacles, the mothers communicated a strong sense that completing the *schooling journey* was a necessary but frequently negative experience for their children.

Against the context of contemporary parental aspirations described in Chapter 1, each mother had relatively modest expectations about what her child might achieve at the end of the *schooling journey*. Certainly, the participants hoped for completion of Grade 12 and ‘some sort of certificate’. But they had more holistic expectations for their children’s *learning journeys* and hoped their child would achieve what Mary described as the *building blocks* for adult independence. They were not specific about what this entailed but it appeared to combine basic academic competencies that were often achieved through outside-school tuition and interventions; ‘soft’ skills and emotional intelligence; and positive character traits such as resilience.

Within the collective narrative of *The Learning Journey*, each mother had a story about her child’s diagnosis as a crucial moment, which occasioned contrasting emotions. For some, a diagnosis legitimised both the mother’s concerns and *struggles* on her child’s behalf, and the child’s own *struggles*. Diagnosis provided an answer to the questions posed by years of anxiety, academic failure and social isolation, and a name to their child’s problems. For Michelle, Eloise and Eileen, diagnosis provided a *plan* for their children’s schooling – with a diagnosis, they all knew how to proceed and get *back on track*. However, a diagnosis also implied limitations and did not necessarily ease their *schooling journeys* – both Mary and Frances, who struggled with the diagnostic process, made the point that not all students get the help they need, regardless of their diagnoses.

Collectively, the participants’ concerns for their children’s wellbeing and wellbecoming focused on their beliefs that mainstream school environments are generally unsupportive of the needs of neurodiverse students. They worried about the immediate and cumulative effects of academic failure or social isolation on their child.

### 6.2.1. Fish Out of Water – concerns for wellbeing

The salient feature of both the visual and verbal metaphors relates to what we know about fish and the environments in which they belong. This knowledge is mapped on to the mothers' metaphorical thinking about their child's needs and the type of school environment in which they belong. Within the collective narrative of *The Learning Journey*, the contributing narrative *fish out of water* tells of these mothers' expressed concerns about the immediate impact of unsupportive classroom and school environments on their children's wellbeing. The participants explained how the usual parenting concerns they felt for their other, typically developing children's, academic and social development were exacerbated, for their neurodiverse child, by evidence of that child's inability to fully participate at school.

The participants framed their children's anxiety in terms of its impact on daily life, such as how it affected sleep, mood, and willingness to socialise or attend school. These were the visible and outward signs interpreted by the participants when their children could not explain their own emotions, or when there was limited communication from school. They explained their children's sense of disconnection from the school academic or social environment through spatially orientated metaphors and described their children's desire to be at the *same level*; their need to *fit in* with their peers; or their fears of being *thrown out* of social groups. Four facets of *fish out of water* outline the participants' assumptions about:

1. the source of their child's anxiety
2. the relationship between their child's anxiety and academic pressure
3. the relationship between their child's anxiety and social isolation
4. the impacts of teacher attitudes to inclusion and of systemic school factors

#### 6.2.1.1. Sources of anxiety

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*'It's just this pressure build-up inside their heads'; 'A meltdown'; 'A blow up'; 'He shut up shop'; 'The wheels were going to come off'; 'you could see her shrinking'; 'Everything falls apart'*

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The participants' narratives about their children's wellbeing focused on the impact of the school environment rather than on a personal tendency to anxiety. They spoke in terms of belongingness and connectedness in the school's learning and social contexts, and each mother described two essentially different children: the 'child at home' and the 'child at school/ in the classroom'. They talked about their child's social and physical confidence in areas where they excelled or felt in control, and stressed that these were not activities normally associated with inherently anxious people: Cate's ability to relate to customers at work; Forbes' love of motorbikes and of working on the family farm; Emily's gregarious, happy nature as a pre-schooler; Rory's sporting abilities and popularity with his peers; and Henry's competence in drama and music.

Each participant spoke about her child's good fortune in having caring and supportive families, and in all cases, at least one good friend. They described their child's overall resilience and ability to cope with adversity on a day-to-day basis at school. However, they also spoke about the way their child's daily interactions in the school environment eroded that resilience. Each mother reported that her child had, at significant points in their *schooling journey*, experienced extended periods of stress. They described the regular tears associated with completing homework or assessment tasks or as Eileen described, the 'fear and terror' of simply having to sit through classes they did not understand. They all described a disengagement that was manifested in reluctance or refusal to attend school, and social withdrawal.

Through metaphors of pressure and release, the participants described how this stress and anxiety would gradually *build* until their child experienced an acute reaction such as Henry's *meltdowns* at school and Emily's night terrors. Mary, Eloise and Frances recalled how their sons cried at the thought of going to school. Most poignantly, Michelle described Cate's weight loss and eventual emotional breakdown. In summary, these mothers attributed their children's anxiety to their interactions in school contexts.

#### 6.2.1.2. The relationship between anxiety and academic pressure

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*'It all just goes over your head'; 'They're full on all day'; '[the classroom environment] is not a perfect fit'; 'He was falling through the net'; 'he struggled with learning'; 'an alien language'; 'making that anxiety grow'*

---

The participants' children were included, to varying degrees, in mainstream classes. However, their inability to participate on the same basis as their peers was a constant source of stress. Each child experienced significant learning difficulties, most notably literacy issues and poor executive functioning associated with their (often overlapping) diagnoses of Dyslexia, NVLD, ADHD and ASD. Their mothers identified several sources of academic *pressure* for these children: the key focus on literacy skills in all learning areas; and the challenges of time management, of following classroom instructions, in organising learning materials, and of breaking down tasks.

When they discussed their child's inclusion the participants discussed the school's capacity and willingness to provide appropriate and adequate resources and instruction. They felt that, if adjustments were made to the classroom environment, learning activities or assessment tasks, they rarely met their child's specific needs. Instead, they used metaphors of fit and compatibility to explain how their child was expected to adjust to existing school systems and structures. Mary's description of Henry as a *round peg in a square hole* and Eileen's fear that Emily's difference from her peers would make her a *fish out of water* explain these mothers' concerns that their child's 'inclusion' in the learning environment was little more than a token gesture.

The mothers described how their children's learning difficulties adversely influenced how they assessed their own capabilities and how this increased their perception of academic *pressure*: not only were they unable to *keep up* with their peers, but they felt that they never would be able to do so. Each mother was in no doubt that her child’s anxiety stemmed from these negative perceptions and from the realities of persistent academic failure.

When they discussed their perception of what triggered their child’s anxiety, and posed as barriers to their child’s academic success, the mothers identified:

- tensions around their neurodiverse child’s ability to meet curriculum expectations
- the implications of being unable to meet Year level literacy and/ or numeracy demands, and
- their child’s sense of shame and stigma associated with not achieving at the same level as their peers.

The narratives revealed a number of tensions around academic achievement, curriculum expectations and the participants’ perceptions of their child’s ability to meet those expectations. On the one hand the participants wanted their child’s educational experiences to be free from what Graeme Innes (2015) has called ‘the soft bigotry of low expectations’, so their narratives emphasised a desire for their children to have the same experiences as their peers and the same opportunities to reach their potential. The mothers communicated expectations for their child’s academic or social progress that were informed by their parenting experiences with older siblings, comparison with their child’s peers, or media discussions about national education standards. They understood that, in order to *fit in*, their children’s academic progress needed to be measured according to Year level standards and, in this respect, these mothers expressed a shared concern about their children’s *schooling journey*:

> He just wasn’t *going anywhere* with his reading (Eloise)
>
> It was fairly evident to me that he wasn’t *making any progress* (Frances)

At same time, their narratives communicated frustration with the way success is measured at high school, and the value placed on a narrow spectrum of abilities. The participants interpreted the focus – in the media, in other parents’ conversations, and in parent-school communication – on NAPLAN results and OP scores as destructive to wellbeing, and as a failure to recognise and celebrate alternative abilities and strengths. They expressed their perception that success in assessment, especially at high school level, is valued over individual progress or effort, and that marking criteria do not account for the difficulties neurodiverse students must overcome.

Yet each mother also expressed a concern that her child's grades were not an accurate reflection of ability. For these mothers, there appeared to be a constant accommodation between what they felt their child could achieve, their perception that their child's abilities did not *fit the standard pattern*, and their concerns over excessive *academic pressure*.

The participants worried that teachers failed to recognise their child's potential. They worried that their child's inability to learn in the same way as their peers was viewed as academic failure rather than neurocognitive difference. They worried about the impact of their child's awareness of these views. And they worried about evidence of their child's increasing disengagement from school. They spoke of how, in unsupportive classroom environments, their child's *struggle* to achieve eroded any joy they might have had in learning. Michelle described a shared perception of their children's experience when she said that Cate 'felt like she was constantly failing'.

The participants discussed the need for different expectations and success criteria based on personalised learning and individual progression. They wanted teachers to encourage their child but not to *push* them to the point where anxiety hindered success; and they stressed the importance of enabling neurodiverse students to have a sense of achievement and recognition of effort, regardless of grades. They each spoke about the necessity of finding a balance between developing individual strengths and achieving a level of academic achievement at school that would translate to 'marketable' skills in the adult world.

The narratives revealed a concern for the implications of being unable to meet Year level literacy and/ or numeracy demands. The mothers emphasised that their children's literacy issues prevented them from fully participating in daily classroom activities, and that assessment protocols did not reflect their abilities. The participants stated that their children were rarely given enough support in exam situations: without someone to read the exam or scribe, these students were unable to effectively communicate subject-specific content knowledge or read word problems in maths or Science. As Michelle stated:

> [Cate's] always been good at maths, but there's a lot of English in maths

Autonomy in learning was a key issue, especially in high school, and the mothers revealed the tension between the degree to which they needed to supervise homework and assessment and their child's need to *keep up*. While they did not begrudge their own efforts to support their child's *learning journey* and were focused on finding ways to *unlock* their child's abilities, they also expected their child's teachers to work out ways to help them achieve and overcome their difficulties, without being overly reliant on teacher aide support. Although Eileen emphasised the way her teacher aides enabled Emily to participate in mainstream classes, Frances, Mary and Eloise were concerned that their sons were 'over-assisted'. The mothers identified specific practices that they felt would allow their child to develop more independence, such as the explicit teaching of effective time management and organisational skills, and fewer and more explicit instructions. Their child's eventual independence, at the end of the *schooling journey*, was a key goal and constant concern for these mothers.

The participants' narratives revealed that a significant contributor to their child's anxiety was their sense of shame caused by not achieving at the same level as their peers, and the perceived stigma attached to learning difficulties and difference. They highlighted an important issue for mainstream inclusion practices: although these children required individualised modifications to instruction, learning activities and assessment tasks, their sense of belonging rested on a need to be seen as 'just like the others':

> He said, "I don't want my classmates to know that I'm *struggling* to read it" (Eloise)
>
> She thinks the other kids think she's doing what they're doing (Eileen)

The mothers explained that their children needed support but not separation from their peers, and this created another dilemma. They all spoke of the necessity of obtaining a medical diagnosis; of the need to prove their child's disability; and to *label* their child's difficulties to ensure additional support at school. Without diagnosis they ran the risk of *derailing* their child's *schooling journey*; with a diagnosis, they separated their child from their peers. There was also a tension in the way these mothers spoke of disability: their child's diagnosed 'disability' acknowledged the ways they were disadvantaged in academic or social settings, yet each mother was emphatic that her child was 'disabled' only at school.

#### 6.2.1.3. The relationship between anxiety and social pressure

*'She didn't seem to get other children'; 'radar for anyone that's different'; 'phased out of friendship groups'; 'she would always get thrown out'; 'The playground can be tough'*

Mary and Michelle, whose children experienced social and behavioural difficulties associated with their diagnoses of ADHD and ASD, highlighted issues of social belonging and connectedness as triggers for their children's anxiety at school. They also described the tension between Cate and Henry's personal characteristics – their social skills and mannerisms; their inability to remain focused or regulate emotions – and teachers' behavioural expectations. They felt these were informed by what is developmentally typical, but not necessarily realistic for these adolescents.

The participants felt that Guidance Officers or Learning Support teachers did little to help staff or students understand what it means to live with a neurocognitive difference but placed the onus of *fitting in* on the individual and individual strategies. However, Cate's situation does appear to have been especially difficult for all involved, as she did not feel as though she belonged with the other girls in learning support, and therefore rejected the school's attempts to support her social needs.

Eileen and Mary reported how Emily and Henry had smaller friendship groups with similar issues or interests among their peers. They felt secure in these friendships and were uninterested in the *dramas* of the mainstream social groups. For both Emily and Henry, social media provided a non-threatening social *outlet* and *connection* based around special interests.

Neither Frances nor Eloise have had concerns about Forbes' or Rory's ability to *fit in* socially. Both boys have well-developed social and sporting skills and experienced a strong sense of belonging within their mainstream peer group: their strong friendships and extended circles of acquaintance were positive aspects of their school experience and appeared to mitigate some of the negative effects of their learning issues. While their experiences demonstrated that these compensatory strengths are important attributes for social *survival* in the school social environment, Frances and Eloise explained how the boys had a genuine concern about being *found out* as different from their peers.

#### 6.2.1.4. Teacher attitudes to inclusion and systemic school factors

*'She just whittled away Rory's confidence terribly'; 'He was very old school … cut and dried'; 'she was just going through the motions'; 'she refused to go with it'; 'Some of [the teachers] just won't budge'; 'we're not going to follow this recipe'*

The participants felt that individual teachers' assumptions about intelligence, and knowledge about neurocognitive difference, were evident in their professional conduct. In their choice of metaphors, the participants conveyed the *diminishing* effects that these attitudes and behaviours had on their child. They felt that some teachers were *pushing back* against directives to include their child and failed to see the connection between their child's learning, behavioural or social-emotional difficulties, their increasing anxiety and their decreasing engagement at school.

Each mother gave examples of inconsistencies in the way individual teachers interpreted their child's behaviour or abilities: Eileen discussed how one teacher assumed Emily was lazy; Frances felt that several of Forbes' teachers attributed his issues to low intelligence rather than Dyslexia; Eloise recalled how Rory's Year 4 teacher felt he was just not working hard enough; and Mary discussed how some of Henry's teachers misconstrued his behaviour as oppositional rather than as an anxious reaction to academic pressure. She also stated that some teachers saw his failure to start or complete work as a failure to follow instructions rather than poor executive functioning skills. The mothers felt that, because these teachers failed to understand the challenges their children faced, it was the child who was seen as the challenge.

While the participants described negative mindsets towards disability and difference, this appears to have been limited to a handful of individual teachers. More commonly, they identified systemic issues around best practice pedagogies, or communication about their child's needs that prevented a whole-school approach to learning or social-emotional issues. The participants' narratives also demonstrated inconsistent inclusion practices between schools (especially between primary and high school) and between departments or year levels at the same high school. When these mothers discussed the systemic barriers to their child's academic success in the mainstream learning environment, they identified issues around:

- class organisation
- diagnosis and support
- communication between school professionals

The mothers identified conflicting issues around streamed classes or outside-class learning support groups that illustrated the difficulties of 'doing inclusion'. On the one hand, as Eloise explained, it was important to Rory that his learning issues were not made conspicuous by being in the *bottom* class or attending peer tutoring. On the other, Frances explained that Forbes saw his learning support class as a *safe place*, and Eileen explained how Emily felt comfortable in her learning support class because she was 'working at her *own level*'. It was highly important for all the children in the study that learning support or lesson adjustments were inconspicuous. Given the degree to which their parents focused on their children's strengths and supported a belief in their difference, not disability, the children's shame suggests that negative attitudes to difference and disability were prevalent in their schools. Conversely, the participants identified that when their child felt adequately supported or encouraged in the mainstream classroom, they could complete classwork, assessment and homework tasks. Moreover, they felt comfortable in that environment.

The participants identified inflexible approaches to the provision of learning support that were caused by current diagnostic requirements. In each case, and for most of their children's schooling, their schools required a suitable assessment or diagnosis before support was provided. Mary explained that Henry was eligible for an IEP and additional learning support because of his ASD diagnosis, but not because of his identified and significant literacy issues. She expressed the belief that too few children receive learning support because they are not ‘entitled’ to an IEP. As one such child, Forbes’ diagnosis of Dyslexia did not permit an IEP, or guarantee consistent in-class learning support and modifications, and this was a source of intense frustration for Frances.

Each mother’s identified communication between school leaders, learning support teachers and classroom teachers as significant and systemic barriers to their child’s inclusion and success in the mainstream learning environment. Mary emphasised how teachers ‘act on their own’ and ‘in their room’. She highlighted the autonomous nature of high school teaching but also the fact that Henry might have up to eight different teachers, all of whom taught *behind closed doors*.

Each participant discussed how inconsistent approaches to communication – between teachers at transition points; between class and learning support teachers; between school leaders or Guidance Officers and teachers; and between subject-area specialists at high school – resulted in an uncoordinated approach to their child’s inclusion. This included the failure of high schools to distribute ‘hand-over’ information prepared by primary school teachers; the failure of primary school teachers to pass on or follow-up on important concerns at end of year transitions; and the period of limbo when a diagnostic follow-up was requested (no learning support without a current diagnosis). The mothers read systemic failures in communication as a failure to know, understand or care for their child.

### 6.2.2. Future proofing – concerns for wellbecoming

> *‘There will always be a good spot somewhere for Emily’; ‘the system’s set up now, you’ve got to sort of have a certificate’; ‘so he’s not completely scarred by the experience’; I don’t want to squash [independence] in them’;‘they’re going to be ok in the end’*

The key message that is conveyed by the visual metaphor is that of protection – the vulnerability of the planet (symbolised by the tree within a globe) is wrapped in protection. This understanding about the need to safeguard the environment is mapped on to the mothers' metaphorical thinking about their own need to protect their child. Within the collective narrative of *The Learning Journey*, the participants also talked about the potentially enduring impact of social exclusion and academic failure on their child's long-term material and social-emotional wellbeing. The contributing narrative of *future proofing* explores these mothers' concerns for their child's future wellbecoming. These were two-fold and related both to the potential impacts of experiencing their *schooling journey* as emotionally traumatic, and to the importance of educational outcomes in achieving the 'good life'. They explained these concerns about difference and *fitting in* through spatially orientated metaphors. They were resigned to the idea of their child surviving, not thriving, at school and discussed their aims of *getting them through* without being '*scarred* by the whole experience'. But they also expressed their hopes in terms of *a place* or *a good spot* for their child in the adult world.

Each mother demonstrated an acute awareness of the long-term impacts of anxiety and depression on her child's wellbecoming. The participants were all highly attuned to the emotional implications of Neurodevelopmental Disorders and spoke of their child's heightened risk for anxiety and depression. For example, Michelle could see that Cate's anxiety – as both a legacy of her schooling traumas and as an aspect of her ASD – would intrude into many domains of her adult life:

> She was going to go to uni this year ... But I think that she knows that she might struggle with it… Her anxiety still causes her difficulty on a day-to-day basis (Michelle)

While acknowledging their children's potential for long-term mental health problems, the participants expressed a desire for their children's future happiness. When this aim was unpacked, it became clear that wanting their children to be 'happy' was actually about wanting them to 'flourish' (Seligman, 2011). They framed their children's capacity to flourish in terms of their ability to maintain stable relationships; make good life choices; and secure long-term and fulfilling employment. Although they held the same hopes for their other children, they knew that their neurodiverse child's *path* would be more difficult.

The mothers expressed hopes for their child's emotional security in terms of belonging and connectedness – wanting *a place* for them to *fit in* now and in the future. The mothers reported strong family connections and stressed the importance of having *a safe home* and adults who care and listen as protective factors. They commented on family values and beliefs around conduct and respect and the importance of the ongoing emotional *support* of family.

Economic anxiety underpins many 21st century parenting behaviours and the participants expressed hopes for their child's material security in terms of educational outcomes. They were highly aware of the life-changing importance of success at school and their child's vulnerabilities to the economic and workforce changes of the 21st Century. They both endorsed the idea that 'good' parents take responsibility for their child's academic and social development and felt that educators increasingly and unfairly expected this of parents. They worried about how they could *future-proof* their child and, in the face of constant technological change and fewer opportunities for unskilled workers, these mothers found it difficult to envisage their child's place in the world. Eloise summarised their concerns when she stated that 'I worry about what the world will be like for them':

> [We were] desperate. Just desperate, thinking … "What's he going to do?" (Frances)
>
> Like I think, "well what are they going to do?" (Eloise)
>
> You just want her to get to a level where she can exist in life (Eileen)

Their worries tied in with their perceptions about how success is measured in schools: the mothers reported that their children's *high school journeys* have been conducted in highly competitive school environments where a tertiary education, or a skilled trade qualification, were considered as prerequisites for the 'good life'. While these mothers demonstrated that they are susceptible to the same anxieties as parents of developmentally typical students, their concerns were overlayed by the improbability that their child would go to university, and the very real possibility that their child's learning, social and behavioural difficulties might limit their potential to complete an apprenticeship.

Nevertheless, all expressed hopes that their child's future financial independence would be secured through gaining practical and vocational skills and, by the end of the study, were expressing relief that their children were embarking on vocational education courses, apprenticeships or school-based traineeships. However, there was an underlying sense that their child had been cheated of other choices for their future because their differences made it so difficult to succeed at school. They felt that school had failed their child.

When they discussed their child's current situation, the mothers commented that they felt able to relax their vigilance because things were going well. But then each mother recalled incidents that highlighted her child's underlying needs and that reinforced her concerns for the child's future. Mary discussed a failed exam that sent Henry into *meltdown* and *derailed* progress in other areas; Eileen described how she was aware of the presence of Emily's anxiety, always *just below the surface*; Frances gave the example of a visit to a careers fair where Forbes sat in the wrong room because he could not read the signs and which aroused old insecurities. They each monitored their child's forays into the adult world (first jobs, drivers' licenses, social outings) more closely than they might for their other children, largely because their child's hard-won confidence was so tenuous and fragile.

### 6.2.3. Key messages and principles that emerged from The Learning Journey

These mothers' narratives identified several significant components of their child's social-emotional wellbeing: first, their sense of belonging and connectedness in the school academic and social environments; second, their capacity to achieve, relative to their peers; and third, their ability to succeed independently. The participants observed that their child's wellbeing was negatively impacted when teachers had developmentally inappropriate academic expectations or misunderstood behaviour, and when this resulted in failure, punishment, or social isolation. However, when there was a good 'fit' between teachers' understanding of neurodiversity – and of individual neurodiverse students – their expectations, and supportive practices, the mothers described positive changes in their child's wellbeing. Overall, the participants reported inconsistent professional expectations for neurodiverse children that reflect current discrepancies around defining 'disability' and difference and make it difficult for parents and educators to be on the same page for learning support and inclusion.

A significant body of literature has established that a good 'fit' between child and environment is essential to adolescent mental health and wellbeing (Aldridge & McChesney, 2018; Arslan, 2018; Roeser et al., 2000; Shochet, Dadds, Ham &

Montague 2006). The participants' narratives suggest that the theories of Basic Psychological Needs (Ryan & Deci, 2000) and Stage-Environment Fit (Eccles et al., 1993; Roeser et al., 2000) provide an important context for understanding what a 'good fit' might look like for neurodiverse students.

Ryan and Deci (2000) identified three basic psychological needs: *competence* – achievement and mastery; *relatedness* – the development of positive and mutual relationships with others; and *autonomy* – the capacity to direct our own lives. They conceptualised these needs as the 'psychological nutriments' essential to wellbeing and without which individuals cannot thrive (Ryan & Deci, 2000, p.74). A social context that satisfies basic psychological needs provides the appropriate 'developmental lattice' for healthy psychological growth (Ryan & Deci, 2000, p.74). A social context that does not meet these basic psychological needs thwarts healthy psychological development (Vansteenkiste & Ryan, 2013).

The basic premise of Stage-Environment fit is that schools should provide environments that support students' current developmental needs while scaffolding their developmental trajectories – that is, educational environments need to reflect students' changing developmental needs as they progress through school (Eccles et al., 1993). Obviously, this is complicated in the case of neurodiverse students, whose developmental needs are not necessarily in synch with their peers'.

The current study raises a significant issue about educator confidence in including neurodiverse students in their classes. Educators must understand both the broader implications for learning, executive functioning, and social competency associated with Neurodevelopmental Disorders, and the developmental needs of individual neurodiverse students. For example, in the current study, Forbes accessed an ophthalmic program that enabled him to decode words, but he still struggled with comprehension. However, Rory significantly improved his reading comprehension with on-going speech pathology. Meeting their respective needs for competence cannot be based on assumptions about 'typical' needs for Grade 10 students or even for Grade 10 boys with Dyslexia. Understanding individual student needs and designing teaching and learning programs to meet those needs, is a requirement of APST Standard 1: 'Know students and how they learn' (AITSL, 2017). It also demonstrates both a corporate (in the communal sense of the word) and a ‘personal manifestation of care’ (Noddings, 1995, p. 2).

From the participants’ perspective, achieving this involves more than professional knowledge of the general implications of neurodiversity. It involves regular consultation with parents whose knowledge of their child derives from experience, and from managing and coordinating diagnoses, interventions and professional advice.

From these findings, a key principle of supportive school environments suggests schools must:

***Create developmentally appropriate learning and social environments***

This principle extends theories of Basic Psychological Needs and Stage-Environment fit by considering that, within the broader constructs of psychological needs and age-stage developmental needs, neurodiverse students have both diagnosis-specific, and individual needs.

The mothers’ concerns for their child’s wellbecoming echoed those identified in the literature on contemporary parenting and the issues faced by 21st century parents. These relate to widespread uncertainty about the skills needed for ongoing employment in the 21st century (UNESCO, 2015; Coredata, 2018), and a neoliberal sense of responsibility for helping their children realise their potential (Barr, et al., 2012; Vincent & Ball, 2007).

These concerns for their child’s wellbecoming co-existed with, and exacerbated, the participants’ very real and justifiable concerns for their child’s current wellbeing: they all wanted to know where their child, who struggled to achieve at school, would fit in a knowledge economy. When these mothers discussed the range of skills they considered necessary for the ‘good life’ in the 21st century, they identified the same social, emotional and academic competencies promoted in the Melbourne Declaration (MCEETYA, 2009). However, the participants saw that their children were unable to master academic competencies because of the way mainstream pedagogies and assessments disadvantaged neurodiverse children. They felt that high schools made assumptions around social competencies but did not offer any explicit guidance for the neurodiverse child, or their peers in terms of relating to neurodiversity. And they emphasised that their child's schooling experience had largely focused on academic outcomes at the expense of social-emotional competencies. Lithari and Rogers (2017) consider that 'care-ful' teaching and learning spaces and practices are not promoted by 'the privileging of academic proficiency' (p.14) and this is supported by the participants' experiences.

A second principle of supportive school environments suggests schools must:

***Ensure an equal focus on social, emotional and academic competencies***

This principle relates to what Noddings (1995) described as the artificial separation of 'the emotional, academic and moral care of children into tasks for specially designated experts' (p.2). It is this fragmentation, a lack of connection between academic expectations, classroom practices and their child's social-emotional wellbeing, that the participants described as being a significant issue in high school.

## 6.3. Collective Narrative Two: Helping Them Get to the Other Side

Each mother explained her parental role through metaphors that highlighted the conceptual metaphor of PARENTS ARE PROTECTORS; the collective narrative of *Helping Them Get to the Other Side* illustrates how the participants fulfilled this role. When the mothers talked about their children's academic failure or social isolation, they communicated not only the real risks to wellbeing and wellbecoming, but their own sense of desperation and need to help. They felt their parental role was to do whatever it took to get their child through to the *other side*, that is, safety and security in either their adolescent present or adult future. They felt that this end justified being highly engaged in their child's cognitive and social development and highly involved at school.

Bronfenbrenner (2001) believed that having an adult who was 'crazy' about them made all the difference in a child's developmental outcomes. While each mother's narrative ended on a note of hope – they felt that their child was going to be ok –they believed that their caring efforts in their child's learning journey and their determined interventions in their child's schooling journey and have made that difference.

The participants described their parental role through four contributing narratives: their perceived mothering responsibilities; their efforts to support their child's learning journey; their perceived need to supervise their child's schooling journey; and their perceived responsibility to advocate for their child.

### 6.3.1. Lifting the pressure – These mothers' perceived mothering responsibilities

*'he still needs that support behind him'; 'he needed a bit of back-up to get him through'; 'it was a softer way of doing it, easing him through things'; 'I had been his support network'; he would have crumbled'; 'finding his feet socially and emotionally'; 'continue carrying them through the fog'; 'a very gentle school'; 'the Learning Support family'; 'go somewhere nurturing'*

The visual and verbal metaphors both relate to what we know about the myth of Atlas bearing the weight of the sky on his shoulders. Atlas' salient features, his strength and endurance, are mapped on to the mothers' metaphorical thinking about the ways in which they needed to support their child.

A significant finding of the current study, outlined in the previous collective narrative, was the mothers' sense of responsibility for their child's social-emotional wellbeing. Walzer (1996) called this 'mother worry' [emphasis in original] (p. 222) and Ciciolla and Luthar (2019) describe it as vigilance over the child's emotions. Within the collective narrative of *Helping Them Get to the Other Side*, the contributing narrative, *lifting the pressure*, explains the participants' 'motherly' concern that underpinned their role in the parent-school relationship and their supportive efforts in providing outside-school support for their child. The mothers described this concern through metaphors of care and spoke of the importance of a *gentle* and *nurturing* approach to schooling. Furthermore, they described their efforts through embodied metaphors which explain their child's anxieties as *pressure* or a *burden*; that conveyed their own need to *lift that pressure*; and to *support* and *carry* their child through their learning and schooling journeys.

A key theme in each mother's narrative was the way they described their mothering work, which included the invisible 'emotional work' (Miller, 2017) or 'mental labour' (Walzer, 1996) of worrying about, and feeling responsible for their families. And it included the visible work involved in being the parent with primary responsibility for household management and childcaring. In the current study, responsibility for their neurodiverse child's learning and schooling journeys overlaid these mothers' everyday parenting work as well as the work that Mary, Michelle, Eloise and Frances did outside the home.

While fathers tend to be the 'breadwinners' in most Australian two-parent families, households where both parents work are increasingly becoming the norm. However, despite doing 'the lion's share of housework', Australian women have taken on the double responsibility for paid work and household management (AIFS, 2016). Ciciolla and Luthar (2019) describe this as the responsibility for being the 'captains' of their households, a role which takes a significant physical, mental and emotional toll. There is a general public perception, supported by research evidence, that Australian parents are experiencing difficulties juggling the commitments of family and work and that mothers do more of this juggling, tend to adapt working hours to their children's needs, are responsible for child care, and are under considerable strain as a result (Dinh et al.,, 2017; Henderson et al., 2015; Volmert et al., 2016).

These gendered divisions of household management and paid work-responsibility for matters of childcare and family-school interactions, and the burden of household 'captaincy' – are borne out in the experiences of the study participants. These mothers explained that this was a joint decision, arrived at after discussions around who should assume this role within the parenting partnership. They described the material and moral support provided by their partners as invaluable, given the intensive nature of this parenting role and the financial costs involved in supporting their child's education. However, while this might have been a shared parental concern, the mothers communicated their feelings that it was primarily a maternal responsibility. They talked about their responsibilities in an embodied, physical way that appears to conform to some kind of mothering ideal of needing to 'be there' for their child (Miller, 2017) – wherever their child needed them to be – whether that meant comforting them through their night terrors; sitting with them while they struggled with homework; or supervising friendships and social interactions. Most of the mothers described having to be *on hand* to collect their child when school became too much; many of the children had been chronic school refusers. Eileen summarised this type of caring as 'such a mothering thing to do' but it also imposes limitations on these mothers' lives; how can the primary caregiver hold a fulltime job outside the home in these circumstances?

Underlying some of these mothers' narratives was a largely unspoken acknowledgement that there is another life 'out there', in the working world that is no longer open to them, because of their primary caring role. Mary discussed the career options that she felt were no longer feasible for her and described her maternal role as her *full-time job*; except that it was not her only job. In addition to managing Henry's schooling and learning journeys, she had the primary care responsibility for the four other children in the family; worked part-time; and participated in parent support groups. Eloise described her roles of Rory's co-therapist and manager as *cumbersome* and *tricky* because she also managed her other children's lives; helped to run the family cattle property; and was an active member of the P & C; all with the added complication of overcoming distance from services and schools. Frances discussed the difficulties of trying to *balance* Forbes' learning needs with the family's needs: her husband's work was tied to the family farm; her work was local; and she had other children at school in the district. Yet she still contemplated how she could enrol Forbes in a program that was suited to his learning needs but based in Canada. And when she found a 'local' school using the program, it was still 100 km away. Each of these women was juggling paid work, volunteer work, the emotional and mental work of being the parent of other children, and the primary caring responsibility for their neurodiverse child's schooling and learning journeys.

Added to these mothers' mental load was the financial burden of trying to support their child. Each mother commented on the cost of assessments, programs and interventions, as well as the travel and accommodation involved for rural and regional parents when services were unavailable. They estimated that they would have spent 'thousands' of dollars over and above the types of enrichment activities enjoyed by their other children. Hays (1996) calls contemporary parenting 'child-centred, expert-guided, emotionally absorbing, labour-intensive, and financially expensive' (p. 8) and this accurately describes the parenting experiences of the mothers in the current study.

### 6.3.2. Case managers

> *'I would have to manage what she was doing'; 'we targeted organisation'; 'you're building a house'; 'that's my full-time … number one job'; 'to get him over the line'; 'to get through that portal'; 'We were putting so much energy into her and it was just wearing her out'*

The visual metaphor of the case file reinforces the verbal metaphor of the case manager. The parents' experiential knowledge of the case workers' role was mapped on to the additional tasks they all assumed out of concern for their child's holistic wellbeing. The participants acted as co-educators, co-therapists and co-ordinators of their child's learning journey. Within the collective narrative of *Helping Them Get to the Other Side*, the contributing narrative, *Case Managers*, explains how keeping track of their child's additional educational support, and medical, mental health and allied health interventions was a significant aspect of the participants' 'mothering responsibilities'. The mothers described these efforts through construction metaphors and spoke of *scaffolding* their child's development; opening *doorways* or *portals* for their child; and providing a *safety net* so their child did not experience continued failure. Each child received support from paediatricians, occupational therapists, speech pathologists, and educational and clinical psychologists – the more complex the child's needs, the more services the parent needed to source. One aspect of taking on the role of *case manager* was working out the education system and the implications of educational, medical and psychological diagnoses: each mother reported her frustration with access to services and with the lack of coordination or communication between systems and within systems. Those mothers who were able to access private medical services had better success in achieving a timely diagnosis. However, they still had to coordinate the diagnosis, inform the school learning support team (and individual teachers at high school) and follow up on health services. In the absence of integration and cohesion between services, another aspect of the mothers' *case manager* role was bridging this gap.

These mothers identified a degree of 'professional' knowledge that they had gained as a response to the educational, medical and allied health worlds that they moved between, and in their role as co-therapist and co-educator for their child. Hodge and Runswick-Cole (2008) call such parents 'para-professional[s] in the disciplines of medicine and education' (p. 7). However, the participants did not assume this responsibility with enthusiasm. The mothers' stories also raise questions about the perception of individual responsibility that is encouraged in neoliberal societies (Savage et al., 2013; Vincent & Ball, 2007): not only did each mother feel individually responsible for her child's cognitive and social development, but received the impression from her child's school that a high degree of responsibility was expected of parents of neurodiverse children.

Knight (2018) suggests there is a risk, when parents do such a good job of taking responsibility for their neurodiverse child's needs, that the burden on families will be downplayed; even when coordinated assistance could provide a better outcome for the child and their family. Eloise and Eileen accessed a private, multidisciplinary practice of paediatricians, psychologists, speech pathologists and occupational therapists and they reported high levels of satisfaction with both service provision and outcomes for their children. However, this service was expensive and located in Brisbane, which added to the existing burden typically experienced by rural or regional families (Halsey, 2018) and made it unfeasible for other families in the study.

Because of limited access to services, the mothers also spoke of a considerable time gap between noticing their child's difficulties; realising that something needed to be done; perceiving that the school was either doing nothing or too little; and then finally seeking outside help. They discussed being hindered by systemic delays (in

Catholic Education or Education Queensland schools), the necessity for additional assessments (in independent schools), or availability of services (in rural Queensland). But first, they had to overcome the uncertainty of knowing where to turn for assessment or diagnosis.

#### 6.3.2.1. Efforts to source information and develop social networks

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*'trying to find answers … is frustrating'; 'she'd heard of it through friends'; thanks to that network'; 'I was still in touch with the Arrowsmith mum'; 'Professional help … set us on the right track'; 'you crave information'*

---

A key element of this contributing narrative was the mothers' efforts to understand the nature of their child's issues, and to discover and access sources of support. Michelle spoke of having 'no idea' and no understanding of what to do, and this highlighted a common issue of access to accurate information. Each mother's narrative described a personal *parenting journey*, that unfolded alongside her child's learning and schooling journeys, and that was communicated through directional metaphors related to searching and investigation. They spoke of the way they *found* the *right answers* – through professional support or personal *networks* – by staying *in touch* with the *right people*, through trial and error, and following productive *avenues*. The participants demonstrated that, without professional assistance and guidance, it is not easy for parents to discover what is *going on* for their child or to know how to help.

When these mothers spoke of their efforts to understand their child, they commented on their intuitive sense that 'something was not right'. Apart from issues around finding an education or medical professional who was receptive to these concerns (which are discussed in the story of *falling on deaf ears*), the mothers also identified that they did not initially know whom to ask or where to go for advice. For each of these mothers, especially at the beginning of their own *parenting journey*, there appeared to be some misunderstanding of the role of medical or mental health professionals, or about the types of assessments that would result in the most effective actions at school or in outside-school support. The participants reported being given inconsistent advice about disability provisions in schools and only Mary (who is a health care worker) discussed going to their General Practitioner as a first point of call. Additionally, their narratives illustrate the uncertainties around diagnosing Neurodevelopmental Disorders, even among medical professionals. None of the professionals in Forbes' country town appear to have recognised his Dyslexia; Mary talked of her dread of having to re-visit Henry's diagnosis with a new paediatrician and Michelle described a '*diagnostic merry-go-round*' when she discussed Cate's changing diagnosis.

These narratives supported some of the discussions around the positioning of parents as pedagogic subjects by parenting experts in the media, parent advice manuals, and in parenting programs (Aarsand, 2014). In the absence of coordinated and authoritative advice, the mothers saw that one of their 'mothering responsibilities', and an aspect of their role as case managers, co-educators and co-therapists, was to learn as much about their child's learning, social-emotional or behavioural assessments and diagnoses. When they spoke of their efforts to educate themselves, these mothers discussed how much they appreciated workshops and seminars organised by advocacy bodies such as Speld, and they indicated that they sometimes took part in parenting discussions on social media. However, *social connections*, particularly other mothers, provided most of their information and support: the participants appeared to value *word of mouth* recommendations. The mothers developed peer *networks* through family and community (such as Eloise's membership of the P & C); through contact with other parents of neurodiverse children whom they met through support groups (as in Mary's case); or through other parents at school. These *networks* either made the school environment more accessible or gave these mothers the confidence to communicate with the relevant education authority.

Relationships with other parents was a key part of the mothers' experiences. While their child's experience and their own efforts to understand and support their child's issues made them feel somewhat separate from the experiences of 'typical' parents, the participants usually described their relationship with other parents in the school community in a positive way. However, peer social *networks* proved to be significant sources of stress for Mary and Michelle, whose experiences echo the negative ways in which others view the behaviour of neurodiverse children, and who experience an associated, or ‘courtesy’ stigma (Farrugia, 2009; Francis; 2012 Gray; 2002). They commented on their isolation, especially in high school, and Mary noted that, ‘there’s so much that you *deal with* on your own’. Both felt judged by other parents, but Michelle, in particular, emphasised her own disconnectedness from the ‘typical *parenting journey*’. Her experience, more so than the others’, illustrated the transformative effect of parenting a neurodiverse child (Scorgie & Wilgosh, 2008) that made her ‘a very different [anxious] person’.

#### 6.3.2.2. A holistic understanding of their child’s issues

Another key element of this contributing narrative was these mothers’ rationale for their efforts. An aspect of the research discussion on highly involved parents is the rise of ‘expert parents’ who maximise their children’s development through neuroscience-based advice (Smyth, 2014; Wall, 2010, 2018) and who are ‘carefully orientated towards the consumer market catering to pregnancy and parenting’ (Johnson, 2014, p. 331). While such parental efforts are commonly directed towards providing some sort of competitive advantage against the uncertainties of the 21st Century, in the current study these mothers’ efforts should not be seen as helping their child to *get ahead*, but as helping their child to catch up or *get back on track*. The mothers spoke of themselves as careful consumers of educational products such as after-school tuition services, however this was their way of helping their child to *fit in*, not gain advantage over other children. They organised and coordinated the extracurricular activities and services that they felt would help address what they saw as deficits in their child’s academic or social-emotional development. They viewed music lessons or sports participation as enabling their child to develop existing strengths and talents and reinforce self-esteem, and to find enjoyment when school was so challenging. They thought sports teams and youth groups might *fill a gap* in their child’s social *networks* when these were missing at school.

These mothers all felt that their efforts were ad hoc and would have benefited from *targeted* advice. Their narratives suggested that limited availability of evidence-based assessment services, long waiting lists and desperation can make parents vulnerable to less authoritative assessments and interventions. The mothers spoke about accessing a range of proprietary therapies – kinesiology, nutritional supplements and restrictive diets, alternative ophthalmic approaches and Brain

Gym® – that do not have the support of medical professional bodies, lack empirical evidence, and which can lock consumers into expensive programs (Stephenson, 2009). These experiences illustrate that while these parents valued informal 'hot' or 'grapevine knowledge' (Ball & Vincent, 1998) that is typically accessed through face-to-face social networks, social media (Schoenbeck, 2015) and online information sources (Dworkin, Connell & Doty, 2013), schools have an opportunity to provide parents with formal and accurate information.

When they discussed their efforts and the lack of alignment between services, the mothers admitted that the search for the right form of assistance for their child was overwhelming. They commented that they were continually asking themselves, 'Did I make the right decision? Is this the right school / doctor / diagnosis for my child? Am I doing enough?' and noted how this incessant decision-making was exhausting and stressful. Although Eloise received support from Rory's teaching Principal and Eileen eventually received advise from Emily's primary school Counsellor, for the most part, the participants reported that they were frustrated by the lack of expert advice from their child's school.

These stories raise questions about the way schools can be 'catalyst points' (Reupert et al., 2015) to support parents as they support their child. The mothers took it upon themselves to find *avenues* of support, with varying degrees of success and each mother's narrative demonstrated that access to reputable services and successful outcomes for her child depended on her ability to *discover* and access them. In the absence of professional advice, this meant having a sufficiently broad social *network* and being able to commit personal and financial resources.

While the mothers asserted their efforts were motivated by a desire to *level the playing field* for their child, rather than by a desire to 'transmit advantage' (Lareau, 2002, 2011), they nevertheless leveraged middle-class financial, social and cultural capital to boost their child's developmental outcomes. And they were aware of this fact: given that just one aspect of their support, private academic tuition, cost these parents upwards of $50 per hour, the activities in which the participants' children engaged can only be viewed as 'elite' activities (Bennett, Lutz & Jayaram, 2012) and not accessible to all. The participants repeatedly asserted that, had they not invested their personal and financial resources into their child's learning journey, their outcomes would not have been so positive. Warren and Edwards (2017) found that family disadvantage translates into lower cognitive outcomes for children because of parents' inability to invest in the type of cognitively stimulating activities or private services accessed by the participants. This is a matter of social justice, as unequal access to resources clearly limits the capacity of families to support their neurodiverse children.

### 6.3.3. Keeping a finger on it – Vigilant supervision

> *'Keeping a finger on it'; 'Getting in teacher spaces'; "what's the best way to deal with it all'; 'It just needed that little bit of a stepping stone'; 'should I be more on top of this?'; 'that's when I came further'; 'I said, 'I need you to be on top of this"; 'we decided then to pull him out'*

The visual metaphor, and the colours chosen, represent danger and the need for attentive awareness. Our knowledge about the focus required to take a pulse, and the importance of that action, are mapped on to the mothers' metaphorical thinking about their need to be attentive to their child's needs, and the dangers to wellbeing inherent in their school environment.

Thomas, Keogh and Hay (2014) found that in their talk about parents, Australian teachers constructed a strongly moral idea of what constituted 'good' and 'not-so-good' parents. 'Good' parents are involved in their child's education to the point that they supervise extra-curricular school activities that complement the work of the school at home. There is also an expectation that parents hand over their supervisory role to education professionals whilst the child is at school. Within the collective narrative of *Helping Them Get to the Other Side*, the contributing narrative, *keeping a finger on it*, explains how the participants stepped out of their expected roles. Their narratives revealed a shared belief that the 'work of the school' had not adequately addressed their neurodiverse child's issues or supported their needs, and each mother felt that her child's vulnerabilities in the mainstream schooling environment made it necessary to closely monitor their schooling journey. The concept of supervision, as motivation for being highly involved at school, was a recurring theme and was expressed through metaphors of control, management and vigilance.

The story of these mothers' vigilant supervision centred on conditional trust – each mother explained that her trust in the school was based on her perception of the school's capacity and willingness to support her child's needs: when she could see her child was participating and achieving; and when she felt her child's learning journey was *on track* due to the efforts of school leaders, Learning Support and classroom teachers. In the face of such evidence of care for wellbeing and progress in the learning journey, when these mothers felt confidence and trust in the school, they felt they could relax their level of supervision:

> I was still *keeping an eye on things*, but I was confident (Eloise)
>
> … and now she's *comfortable* with it [learning support] … I rarely have to ring up (Eileen)

There was evident relief in these statements because their narratives indicated that, in other circumstances, the mothers would have preferred a less involved relationship with their child's school; they wanted to trust the school to manage their child's schooling journey. Eloise expressed this general feeling when she explained that she needed and wanted to *hand over* the responsibility for Rory's education to his teachers and school leaders. The mothers communicated the sense that, ordinarily, they were not uncomfortable with traditionally 'accepted' forms of involvement such as volunteering for tuckshop and the P & C. They do not appear to have questioned the 'insider-outsider' status of education professional and parent in terms of curriculum and pedagogy until their expectations for their child's schooling journey were disappointed.

The participants expected sufficient learning support so their children could participate in the mainstream classroom and experience some academic success, and sufficient emotional support so their children could feel a sense of belonging and connectedness at school. When the mothers described what inclusion looked like for their child, each talked about their child's ability to take part in a 'normal' schooling experience.

With respect to their children's learning difficulties, these mothers did not necessarily expect teachers to *fix* the problem, but they did expect teachers to try to understand and help. They gave considerable credit to teachers who were seen to be making an effort, and they interpreted even quite minimal efforts as evidence of care for their child's wellbeing. While each mother spoke warmly of individual teachers who tried, they rarely described efforts to support, encourage or include their child that went beyond what is expected by the APST (AITSL, 2017). While some teachers did go 'above and beyond', such as the effort Rory's teacher put into supporting his sport, it is significant that these mostly 'ordinary' efforts – trying different methods to explain maths problems to Forbes or recommending a lunchtime tutorial group for Henry – stood out among the narratives as relatively isolated examples.

The participants noted that many teachers had positive attitudes and caring intentions but lacked professional knowledge. They described 'lovely' but inexperienced young teachers whose enthusiasm was evident but who appear to have been unprepared to accommodate neurodiverse students. Eloise felt that Rory's teacher for Year 1-3 struggled with the demands of a multi-age class and rationalised her misplaced optimism about Rory's reading as stemming from inexperience and a lack of professional support. Eileen and Mary shared a similar perception that teachers are constrained in their capacity to care for neurodiverse students' academic and social-emotional wellbeing by large classes and diverse needs:

> I suppose they've got big classes. They don't have time to individualise what these little kids are doing (Eileen)
>
> She's got lots of passion, but she also has *lots* of other kids in that classroom (Mary)

In these excerpts it is evident that, while individual teachers might have appeared to care, systemic issues, that were evident from the first years of school, eroded these mothers' faith in the school's capacity to address their children's needs.

Although each mother described *a point* at which she felt she could relax her vigilance, these moments all tended to occur towards the end of her child's schooling journey and, in Michelle's case, several years after Cate left school. The participants described years of declining trust, and years of increasing involvement. They interpreted their children's lack of progress in their schooling journeys, their social isolation and their increasing anxiety as evidence that professional staff were not demonstrating an adequate level of care. These mothers felt that this warranted a closer involvement with the school, and each was convinced that her child's current wellbeing, and any optimism she felt for her child's future, was due to her vigilant supervision and constant intervention.

The mothers discussed their efforts to be involved in the decision-making process: they influenced timetabling or staffing decisions and anticipated issues with individual teachers; they proactively contacted classroom teachers to inform them of their child's needs; and they organised meetings. Eloise's actions illustrate an intense level of monitoring and described interactions with Rory's teachers that were business-like and based on a perception of equal responsibility for his schooling journey: communicating her intention to 'work with' the incoming Principal at Rory's primary school; personally scaffolding his transition, via a *stepping stone* school, from complete support at home to relative independence at boarding school; and setting up a *support network* among senior teachers, boarding masters and tutors at that school.

The participants' level of trust in their child's school was also influenced by their perception of being 'outside' the school. Erratic home-school communication played a large part in this and made them feel isolated from the workings of the school. Each mother felt that having a clear idea about her child's day would help her to support her child's wellbeing. However, levels of information were inconsistent: Eileen commented positively on the coordinated approach between Emily's learning support teacher and her mainstream class teachers; Mary discussed her frustrating and ongoing efforts to contact each of Henry's teachers individually, which involved repeated emails to which few of his teachers replied, and Frances felt completely ignored and uninformed.

Hence there are two significant aspects to these mothers' supervisory actions: their underlying absence of trust is related to both their perception of professional competency and to their 'need to know' about their child within the school. The mothers indicated that when their child was doing well, their trust in the school's capacity to address their child's needs increased. This supports existing research into relational trust in schools conducted by Bryck and Schneider (2003), Goddard and colleagues (2001), Kochanek (2005), and, in particular, the research of Shelden and colleagues (2010) and Stoner and Angell (2014) into mothers of children with disabilities. Additionally, for the mothers in the current study, proactive and effective home-school communication decreased their ‘need to know’ and consequently, their level of supervision and vigilance. This complements the research of Schweizer, Niedlich, Adamczyk, & Bormann (2017), who note that parents have little personal knowledge of school staff and culture, and therefore take a risk in entrusting their child to the school’s care. Parents attempt to mitigate this risk by seeking information about the school and become involved to find out about their child’s schooling experience.

### 6.3.4. Taking a stand – Perceived responsibility to advocate in the school environment

*‘I push in the IEP’; ‘Someone needs to be taking a stand’; ‘I need to step in’; ‘I think you need to be a helicopter parent’; ‘I had to stand up for her’*

The powerful fist is a common representation of activism and advocacy and visually reinforces the mothers’ metaphorical thinking about their need to actively represent their child’s interests. Within the collective narrative of *Helping Them Get to the Other Side*, the contributing narrative, *taking a Stand*, addresses the way these mothers talked about their sense of responsibility to advocate for their child in the school environment. They explained that being highly involved in their child’s school – and they all felt the stigma of being considered overinvolved – was absolutely necessary to help their child through their schooling journey. While they were uncomfortable with this role, their commitment to support their child overrode this uncertainty and discomfort. They talked of the lack of inclusion provision for their child, and their sense that they were being excluded from decision-making, which diminished their trust in the school. These factors increased their perceived need to advocate for their child.

This commitment was suggested in the mothers’ narratives through defensive and martial language. In keeping with the conceptual metaphor of ADVOCACY IS WAR, the mothers talked about their perceived need to *take a stand* and *stand up* for their child; their need to push for recognition of their child’s needs, and of their own *struggle* to access effective support. And they talked about their need to be brave and *strong* in their dealings with education professionals because they felt that when they *stepped in*, they were *crossing* some tacit *boundary*. Accordingly, these mothers' narratives describe a reluctant advocacy, and a perception that they were stigmatised for being *helicopter mothers*.

There are five strands to this contributing narrative, as outlined below

#### 6.3.4.1. Parental responsibility

The mothers explained that their advocacy was motivated by their child's vulnerabilities in the school system; a perception that their child's needs were unacknowledged, and a sense of basic parental responsibility to protect and represent their child's interests:

> When it is evident that your child is not learning …then you have to start advocating for them (Frances)
>
> If you're not in there, *making a stand* and being an advocate for your child …your child won't be included (Mary)
>
> I had to [advocate]… when you're a parent, who's going to do it? (Michelle)
>
> These children need an advocate which is your job as a parent (Eileen)
>
> He is not going to succeed on his own without intervention (Eloise)

There was an added sense of their obligation as 'good mothers' and that entailed a responsibility to ensure that teachers, leaders and support staff cared for their child's academic and social-emotional wellbeing in their role as proxy parents. The mothers explained that teachers must '*split* their care' in as many ways as there are children in their class and each parent commented on class size, noting that even the best teachers cannot care for everyone. This seemed to be one of the most poignant and significant messages conveyed in the participants' narratives – that in the haste to *push* children to succeed, the caring aspect of teachers' work is being lost.

The mothers communicated their belief that they are the best advocates for their child but would only *step in* if they perceived that teachers either could not or would not care, or that they were unsupported in their attempts to care.

#### 6.3.4.2. Power relationships between teachers and students

These mothers commented on the issue of power in relationships between children and teachers, discussing the way their child's perspective or interpretation of events was not always heard. They each gave examples of ways in which their neurodiverse child was disadvantaged, in comparison to their developmentally typical peers, and how they needed a committed and interested adult to represent their views. This was largely related to the way their child's anxiety manifested in the classroom and the way teachers interpreted either externalising or internalising behaviours. While they saw advocacy as primarily a parental responsibility, they each gave examples of teachers or medical professionals who advocated for their child, either in conversations with other school professionals, or to education authorities.

Mary pointed out that taking your child's part in often confrontational meetings was difficult; it reminded parents of their own school years and the inequitable relationship they had with school staff. The participants therefore saw advocacy as an act of bravery and strength.

#### 6.3.4.3. Making invisible disabilities visible

The mothers felt that they needed to make their child's *invisible disability* visible to teachers or school leaders. They emphasised that their child's 'normal' appearance belied their difficulties and rendered both the disability and the child invisible to teachers: Eileen talked about Emily being '*under the radar* all year'; Michelle felt that Cate's school 'couldn't or wouldn't see' how she was different; Eloise explained that Rory *fell between the cracks* and Mary discussed how Henry would basically disappear or *fall into a big void* without his IEP.

Therefore, part of the mothers' perceived role was to ensure that their children's needs were not overlooked. Eileen explained that her role was to remind Emily's teachers about her difficulties and to repeat the messages, about her anxieties or needs, that got *lost in translation* in home-school communication. Eloise made sure that the Head of Senior School knew who Rory was and was personally *keeping an eye on him*, among more than 1000 other boys.

#### 6.3.4.4. Advocacy as an individual responsibility

The way in which each mother advocated for her child, and her degree of success, seemed to depend on her personal circumstances, such as education, personality and social capital. For example, while Eloise used the support of the P & C to advocate for Rory at primary school, she also had the confidence to engage the attention of a senior staff member at his secondary school. She understood the approach and language that would be most successful, and she had the resources to make periodic personal visits to ensure that her by-proxy supervision was carried out. Frances, who valued personal social networks, talked of her friend who acted as her 'advocate in the room' in parent-teacher meetings at primary school. Eloise, who valued her longstanding family connection with Emily's school, used this to her advantage. Although she did not enjoy being *always up at the school*, she was well-known in that environment. While they all hoped that taking part in this research would change things for other neurodiverse children and their families, the participants expressed little interest in collective activism. Only Mary spoke of taking action to negotiate an *advocacy template* with Henry's school that would benefit other families. Even then, she had no intention of *breaking new ground* or causing difficulties, and she did not want to be seen as interfering or overinvolved. That is, she and all the other mothers, did not want to be seen as troublemakers or *helicopter mothers*.

#### 6.3.4.5. The stigma attached to advocacy

A significant theme in this study was the participants' feelings about being viewed as *helicopter mothers*. There was an evident tension between their sense of agency – as managers, supervisors and advocates – and their sense of constraint when it came to involvement in school. They appeared to have conflicting interpretations of 'appropriate' parent behaviours and their role as 'good mothers' who needed to advocate for their child:

> I had to [advocate], I didn't want to (Michelle)
>
> I've had to [advocate], very much so. Very much so. Which I don't know... I'm trying not to be the *helicopter mother* (Eloise)
>
> You've just got to be the advocate for your child, and you want to be but, oh dear, you feel that *painful parent* (Eileen)
>
> Criticism of highly involved parents, calling them *helicopter parents* is unfair (Frances)

On the one hand, they spoke of the stigma attached to *helicopter parenting* and emphasised that this was not the role they wanted in the parent-school relationship. They would not have chosen such a high level of involvement and they described feeling intrusive and unwelcome. They also felt unfairly judged by staff and other parents for what they saw as a necessary parental responsibility and felt that their justifiable concerns for their child's wellbeing and wellbecoming were misinterpreted as interference. Each mother spoke of the balance, that they were still unsure they had achieved, between their perceived need to advocate and monitor; their need to *step back* for the sake of their child's resilience and developing independence; and their perceptions of 'appropriate' parenting behaviours.

On the other hand, these mothers appeared to be reclaiming the label of *helicopter mother*. By reappropriating what is normally a stigmatising and pejorative term, these mothers were claiming their identities as mothers of neurodiverse children and asserting the value of their 'mothering responsibilities'. Galinsky, Hugenberg, Groom and Bodenhausen (2003) discussed how self-consciously referring to themselves in terms of that label is one way in which stigmatised groups subvert the negative connotations of labels. The mothers in the current study would preface their statements with, 'I don't want to be seen as a *helicopter mother* but …' and it was the qualifying 'but' that indicated that they felt justified in their actions, to ensure their child's inclusion, in the face of the 'ableist discourses and practices' prevalent in their children's schools (Lalvani & Hale, 2015, p. ).

The mothers' ambivalence around their role in the parent-school relationship represents conflicting societal attitudes towards the gendered role of 'good' mothers and 'appropriate' levels of parent involvement in schools (Good et al., 2017). There is increasing concern from education and mental health professionals about the overinvolvement of some parents in their child's lifeworlds, including school, with growing research evidence that intensive parenting contributes to lowered self-efficacy and resilience in adolescents and perpetuated dependence on parents (Reed, Duncan, Lucier-Greer, Fixelle & Ferraro, 2016; Givertz & Segrin, 2014). Professional discourse is reinforced by the negative public discourse around overinvolved parents and these mothers' experiences confirm this public pressure to resist overinvolvement. However, as Blum (2007) identified, there is a complicating measure of self-imposed ‘mother blame’ felt by mothers of neurodiverse children who worry that they are ‘not doing enough’ to support their child.

Additionally, educational and public discourse rarely focuses on the reasons parents might want, or feel a need, to be highly involved in their child’s education (Grolnick, 2014; Padilla-Walker et al., 2019). As the participants commented, parents of SEN students with verifications have accepted reasons for high levels of involvement – they have an active partnership with the school related to their child’s IEP requirements. This is more difficult for parents whose children’s difficulties do not count as a ‘disability’.

Blum (2007) suggests that mothers of neurodiverse children have few available options other than to resort to a kind of ‘vigilante’ behaviour when dealing with education and medical authorities. While the mothers in the current study expressed frustration and anger with these systems and with key individuals; and while their levels of exhaustion, stress and self-doubt corresponded with the way these emotions are experienced by other parents of children with disabilities (Eaton et al., 2016; Larson, 2010; Safe, Joosten & Molineux, 2012), they all expressed a polite desire to work within existing systems. Even so, these mothers were working to effect every-day ‘micro-changes’ in the way neurodiverse children are included and supported in school environments (Ryan & Runswick-Cole, 2008).

### 6.3.5. Key messages and principles that emerged from Helping them to get through

Although encouraging parent participation in education is a key policy direction in Australia, the experiences of these mothers suggests a degree of professional resistance to the idea of parents being highly involved at school, and that such parents are viewed as overprotective and interfering. The mothers’ narratives raise questions about appropriate levels of involvement in schools; and what is appropriate in terms of the burden of support shouldered by individual parents.

The narratives suggest that these mothers saw the school environment as chaotic and disadvantageous to their child and their efforts can be read as a way of attempting to create the type of ‘advantaged and stable environment’ (Bronfenbrenner & Ceci, 1994) that allows for optimum developmental outcomes. While this is arguably what responsible parents do, there is a traditional divide between the work of the school and the work of the parent at home, and the participants' actions crossed that divide.

Each mother demonstrated a strong belief that her child's wellbeing and wellbecoming depended on the fulfilment of her 'mothering responsibility' to manage, supervise and advocate. Consequently, the mothers' intensive engagement in their children's cognitive and social development was directed towards providing a supportive out-of-school environment and towards influencing the school environment, where they could. However, the participants also spoke of the complexities and personal challenges inherent in these responsibilities. The challenges of accessing effective services and information, a degree of social isolation and perceived stigma affected their sense of parenting efficacy – each mother expressed doubt and reluctance. However, these mothers were sufficiently motivated by their absolute sense of responsibility for their child's wellbeing to overcome these challenges.

Burke and Hodap (2016) suggest that, for parents of SEN students, advocacy is not a 'default position' but is related to parents' perceptions of provision for, and teacher attitudes towards, their child's inclusion. The current study confirmed these conclusions and addressed the authors' suggestions for further research into the impact of parental advocacy on the parent-school relationship or the child's schooling experience. The study found that these mothers believed their advocacy efforts had placed them in an adversarial relationship with the school and were concerned that their child might suffer as a consequence. This may have accounted for the fact that the participants were uninterested in collective activism.

In their meta-synthesis of the literature on how parents of children with ASD advocate for their child, Boshoff and colleagues (2018) identified the components of this experience. Themes that resonated with the current study's conclusions included parents' need to create a better future for their child, and in particular, to change their child's environment to better accommodate their needs. However, the studies reviewed by Boshoff and colleagues (2018) were focussed on early childhood, and the mothers in the current study all identified how they had found it much easier to advocate for their child in primary school where they had developed close relationships with Learning Support and classroom teachers. They expressed a strong feeling that systemic issues associated with high schools presented as barriers to their advocacy efforts and that they had to make a more concerted effort as a result. They also perceived a more pressing need to create supportive environments at high school as they saw more threats to their child's wellbeing in this setting.

These findings suggest three key principles for schools if they are to build partnerships with parents based on the support needs of neurodiverse children and their families:

The concepts of 'parent engagement' and 'parent involvement' relate to different parenting activities. If schools are to properly understand how parents participate in their child's education, then they must:

***Encourage parents to share how they support their child's learning and schooling journeys***

If parents are motivated to be highly engaged in their child's learning journey by a perceived need to create a more developmentally appropriate home learning environment, then schools must:

***Empower and support parents with authoritative advice and access to coordinated services***

If parents are motivated to be highly involved in their child's schooling journey by a perceived need to create a more developmentally appropriate school environment, then schools must:

***Attend to parents' reasons for being engaged and involved***

These principles suggest that schools review their place in the community as potential 'information hubs' and places parents want to be. They also imply that schools will have a better understanding of parent involvement when they critically review their learning and social environments and extend an authentic welcome to parents.

## 6.4. Collective Narrative Three: Falling on Deaf Ears

*'A golden key'; 'You can cross barriers'; 'Which way/ avenue to go in' ; 'I'm breaking new ground' 'Called in to school'; 'Going up to school'; 'Went in to see the teacher'; 'Teacher speak' ; 'to find the right way … to go about it'; 'you don't get the picture'*

The visual metaphor of an ear not attuned to the surrounding words supports the mothers' metaphoric thinking about their difficulties in communicating their child's needs to educators.

Within the collective narrative of *Falling on Deaf Ears*, each mother described the difficulties they experienced when trying to develop a working relationship with their child's school. To explain these difficulties, they used metaphors consistent with the conceptual frames of MIND IS A CONTAINER and SCHOOL AS A FORTRESS. These mothers identified specific *barriers* that *kept parents at a distance* and hindered their attempts to support their child's learning and schooling journeys. They discussed their efforts to *find a way* through these barriers and the need for systematic and standardised *pathways* of involvement and communication with schools.

There are five strands to this contributing narrative. When the mothers talked about barriers to effective parent-school relationships they discussed:

- welcome from the school
- educator attitudes to parent knowledge
- communicating about neurodiversity
- expectations around parent involvement, and
- systemic barriers to parent involvement.

### 6.4.1. The school welcome

When the mothers discussed their experiences of visiting the school, they all expressed this as being ‘*called in to* school’ or ‘*going up to* the school’. This conveyed their sense of being both literally ‘outside’ the physical institution of the school and needing to be invited or, on occasion, summoned in, and of being outside the teaching community that ‘belonged’ within the school. When the participants discussed *finding the right way* or the *right avenue to go in*, this referred to their attempts to communicate with teachers or find meaningful ways of being involved at school. Their narratives communicated a sense of a power imbalance in the parent – school relationship that was weighted towards educators.

### 6.4.2. Educator attitudes to parent knowledge

Pushor (2017) explains parent knowledge as the ‘funds of knowledge’ accumulated through the interactions between parent and child in the context of the home. The participants in the current study confirmed this, discussing their understanding of their child that had developed through years of interaction and observation. Each mother communicated the importance of having her child’s issues recognised, and her own concerns validated, by medical or education professionals. They commented that educator confidence in their parent knowledge facilitated their efforts to support their child’s schooling journey and built their trust in the education system. However, their narratives communicated a strong sense of isolation and vulnerability when they perceived a lack of respect for their parent expertise.

The mothers discussed circumstances in which they were discouraged from questioning the professional work of educators, even with clear evidence of their children’s academic failure or social exclusion. Through her metaphor of feeling that everything she was saying was *falling on deaf ears*, Frances expressed the frustration these mothers experienced when they felt that their concerns were ignored:

> I didn’t feel that they believed me … And I was very, very frustrated (Michelle)
>
> [I felt] completely *out of control* of the whole situation (Eloise)
>
> The impact of not being believed by teachers, or having them *downplay* Forbes’ diagnosis of Dyslexia made me frustrated … they made me feel stupid (Frances)

The participants saw that their expertise did not carry as much weight in decision-making about their child as professional expertise, but they questioned this assumption. They explained how their own knowledge, that was based on daily observation and everyday experience, had equal, if not more validity:

> How would they know what it's like unless they have a child with difficulties? (Frances)
>
> They need to know what it means to have a child with these difficulties (Mary)

The mothers' narratives illustrate the central role a medical diagnosis can play in validating parent concerns; corroborating parent observations about their child; and legitimising their role in the parent-school relationship. Eileen described an official diagnosis as 'a *golden key*' and spoke of the authority it conferred, saying it allowed her to *cross barriers* that would otherwise exist for her as a parent. Without a recognised medical diagnosis, the participants felt that schools do not always acknowledge the intensively supportive role that parents play in their children's lives, or the contribution their parent expertise can make towards planning their child's education.

Although disrespectful attitudes towards their experience and expertise did not appear to have characterised the participants' relationship with most teachers, when teachers were dismissive it had a significant impact on these parents' parenting efficacy and confidence in the education system.

### 6.4.3. Communicating about neurodiversity

The mothers' narratives raised the question of whether parents and teachers are *speaking the same language*. Their experiences demonstrated that, until their child had a formal diagnosis or assessment, neither parent nor teacher had a shared language in which to discuss the child's difficulties. With no shared language, these mothers described how difficult it was to work with their child's teacher towards improving outcomes. Although teachers commented on worrying behaviours, or that learning outcomes were not at Year level expectations, they do not appear to have known how to properly explain or interpret these discrepancies. The participants commented that Learning Support teachers, who might have been able to explain or interpret these difficulties, were responsible for too many students.

At the same time, these mothers saw that their children were not fitting in with their peer group; or had difficulties that older siblings had not experienced; or were not achieving specific milestones. However, they also did not know how to explain this or communicate their concerns to educators. It appears that neither parent nor teacher could effectively explain their concerns, other than to comment that *something was not quite right*.

In the stories of diagnosis, one of the most significant outcomes was that some participants were given a language in which to describe what their child was going through. In the current study, these parents had three reactions to diagnostic labels: for Eileen, Eloise and Michelle, the diagnosis provided a shared language in which to discuss their children's social-emotional or learning needs; a systematic and authoritative means of addressing these needs; and credibility for parental concerns.

Mary's narrative illustrated the ongoing requirement to update Henry's diagnosis and the concern that if his diagnosis were changed, that would also affect the shared language upon which Mary's (tenuous) relationship with his school was based.

For Frances, Forbes' diagnosis of Dyslexia was essentially meaningless at his school in terms of in-class support or adjustments. However, from her evident confusion and frustration, the school did not appear to have fully communicated their reasons. Frances noted that, even when she did get the opportunity to voice her concerns, she did not feel part of the conversation about Forbes' needs because of his teachers' use of *teacher speak*, or what she perceived to be the deliberate use of esoteric and inaccessible professional language.

### 6.4.4. Expectations around parent involvement

Education policies describe how to increase parent engagement or involvement and explain what under-involvement looks like, and there is a considerable degree of public discourse around over-involvement. However, as these mothers suggest, there is no clarification around what an ideal level of parental involvement should look like and they argued the need for some kind of 'Goldilocks Principle' or guidelines as to how much involvement is 'just right'.

Yet, as the participants' experiences demonstrate, while clarification and consistency would remove some of the uncertainty in the parent-school relationship, decisions around how much involvement is 'just right' must consider the individual child's needs, and their parent's need to be involved, on a case-by-case basis. Unfortunately, these parents identified that this type of flexible approach to their involvement was rare. Overwhelmingly, their narratives described situations where they were expected to restrict their engagement in their child's education to outside school activities, and their involvement to joining the P & C, attending parent-teacher interviews, and twice-yearly IEP meetings if their child had a verified disability. In other words, minimal face-to-face contact and always at the school's invitation. However, they also described frequent and regular academic and social crises – around assessment time; at the beginning of school terms; whenever there was a school camp or sports carnival – that clearly required more systematic channels for these parents to communicate their child's distress. Because these did not exist consistently across schools, these mothers found it necessary to find their own *way in* and they described efforts to disrupt taken-for-granted patterns of parent-school interactions.

### 6.4.5. Systemic barriers to parent involvement

The mothers discussed the structural and systemic *barriers* to parent participation that were especially problematic at high school and centred around home-school communication. These included the practical difficulties of communicating with numerous teachers; teachers not replying to messages; and teachers not passing on information about critical incidents at school. They commented on the inadequacy of parent-teacher interviews to address issues on an ongoing basis, with Mary stating that, 'you've got a child with needs, but you don't *get the picture* until the end of term… There needs to be *more in the middle*'.

These mothers' 'need to know' was discussed above as a motivation for vigilance and supervision, but their narratives also illustrated how inconsistent protocols for home-school communication led to these mothers feeling isolated from the workings of the school. As the Collective Narrative of Helping Them Get to the Other Side demonstrated, these mothers generally used peer networks to gain information about the school when official channels of communication failed to satisfy their 'need to know'. However, as Michelle's experience demonstrated, mothers of neurodiverse children, especially those who experience social isolation, might lack the type of social contacts within the school community that provide information about and a means of accessing the school environment.

The mothers also described personal factors that served as barriers to participation at high school. They described feeling less confident in knowing how to help their child with homework or assessment; they cited busy family schedules, other children's after-school activities, and the pressure of acting as their neurodiverse child's co-educator and co-therapist.

### 6.4.6. Key messages and principles that emerged from Falling on deaf ears

These mothers' frustrating, and often frustrated, attempts to build a relationship with their child's school resonate with existing research and demonstrate that not being heard or valued appear to be almost universal experiences for parents of children with disabilities: the themes of powerlessness and exclusion feature in research on parent-school relationships in Scandinavia (Lundeby & Tossebro, 2008), South Africa (Meier & Lemmer, 2015), the United States (Ditrano & Silverstein, 2006) and Australia (Keen, 2007). The mothers in the current study felt that effective knowledge sharing was the most significant factor in understanding and alleviating their child's anxiety: they felt that they had valuable knowledge about their child; they wanted to communicate what was happening at home; and they wanted to receive timely information about what was happening at school. Their experiences confirm existing research on the value of parent expertise (Harte, 2009), and parents' desire for teachers to respect their parent knowledge (Pushor, 2017), and to listen to them (Stoner, Bock & Thompson, 2005). They also support other studies that suggest parent knowledge occupies a lesser place on 'hierarchies of knowledge' (Hodge & Runswick-Cole, 2008).

The mothers' experiences also highlight the importance of a sense of belonging and a sense of community for parents as well as students. Pushor (2012) has written about the concept of the school as a 'protectorate' as a metaphor for the ways in which schools use their expert knowledge to 'claim their position as decision-makers in the school' (p.466). In the current study, when these parents felt that they had been left out of the decision-making processes for their child's inclusion, they also felt that they had been *shut out* of the parent-school relationship and of the school as an institution. By extension, they felt excluded from a significant aspect of their child's life and saw that advocacy and supervision were logical responses. As a sense of partnership evolved for Eileen, Frances & Eloise, the perceived need to advocate decreased, this was still a work in progress for Mary and never eventuated for Michelle while Cate was at school.

These findings suggest that to develop effective parent-school partnerships schools must:

***Consult with parents around the development of guidelines for parent participation***

And:

***Involve parents in, and inform them of, the decision-making processes relating to their child's inclusion***

Effective home-school communication is acknowledged as a foundational aspect of effective parent-school partnerships in federal and state parent engagement frameworks (DEEWR, 2017; Department of Education, 2013). However, the current study findings suggest a practice-policy gap and indicated that issues around home-school communication functioned as significant barriers to effective parent-school partnerships. In fact, when participant narratives were checked against the criteria for Communication (Dimension 1) of Queensland's *PACE Framework* (Department of Education, 2013), there appeared to be fundamental differences between policy aspirations and these mothers' experiences. Across the cohort, not one of the criteria were met. The current study highlights the importance of listening to parents of neurodiverse children and the importance of schools and parents working together.

## 6.5. **Conclusion**

This chapter demonstrated that the mothers' lived experience of the phenomenon of the parent-school relationship was captured in three collective and overlapping narratives that were organised around three metaphor 'families' that communicated the participants' collective voice. That three collective narratives emerged, rather than a single essential experience of the central phenomenon, illustrates the complexity of the mothers' lived experiences. The literature discussion in Chapter 2 suggested that, while parental involvement in school and engagement in education are separate constructs, they both exist on a continuum of interest in, and responsibility for, the child's holistic development; and they are both motivated by a responsibility to care. In this chapter, the mothers' collective narratives demonstrate that their 'primary care responsibility' (Miller, 2017, p. 30) underpins all their efforts to support their child's learning and schooling journeys and is central to their role in the parent-school relationship.

Caring is a fundamental parenting activity (Mayeroff, 1965), but the participants described a difference between how they cared for their neurodiverse child and their other, neurotypical children. These mothers felt that their neurodiverse child was more vulnerable in the school environment than their other children and that their child's anxiety was the outcome of a poor fit between their learning, social or behavioural needs and the mainstream school environment. They described attitudes to, and understandings of, disability and inclusion provisions for their child that varied across teachers, year levels and schools, highlighting inconsistencies in the extent to which schools recognised and addressed their children's needs. The mothers explained that they became involved at school because their previous experiences with educators did not inspire confidence in the school's capacity to include, support or care for their neurodiverse child.

Furthermore, they felt that they were engaged in their child's cognitive and social-emotional development to a far greater extent and described a complex schedule of medical, mental health and allied health interventions and enrichment activities. The mothers saw the current approach to learning and social-emotional support as arbitrary, noting a gap between medical, mental health and allied health professionals' assessment of their child's needs, and the support their child received at school. They spoke of their perceived need to bridge this gap and expressed a fundamental sense of 'mothering responsibility' to access all available avenues of support, given their location and financial and social resources.

Above all, running through each narrative was the overwhelming concern, shared by these mothers, for their child's current wellbeing and their future wellbecoming. When these mothers talked about their motivation for being highly involved in their child's learning and schooling journeys, they spoke about both the immediate and the enduring impact of academic failure and social exclusion and their own need to do what they could to support their child.

The mothers not only expressed the idea that their child would take a 'longer road to adulthood' (Arnett, 2015), but also that they would need to be highly involved in their child's life for the duration of this journey. They felt that their child would 'get there' eventually, but their journey would need more scaffolding and support. They perceived that they were stigmatised, by these efforts, as being overinvolved or 'helicopter' mothers and that this set them apart from other parents.

This chapter also developed seven principles to help educators support the wellbeing of neurodiverse students and develop more effective partnerships with their parents. They suggest that schools must:

1. Create developmentally appropriate school learning and social environments.
2. Ensure an equal focus on social, emotional and academic competencies.

3. Encourage parents to share how they support their child’s learning and schooling journeys.
4. Empower and support parents with authoritative advice and access to coordinated services
5. Attend to parents’ reasons for being engaged and involved.
6. Consult with parents around the development of guidelines for parent participation.
7. Involve parents in, and inform them of, the decision-making processes relating to their child’s inclusion

These findings and principles are linked to recommendations for practice in Chapter 7, which concludes the thesis.

# CHAPTER 7: CONCLUSION – THE RESEARCH JOURNEY ENDS

## 7.1. Orientation to Chapter 7

This chapter provides an overview of the study by summarising:

- the research problem and the research questions
- the literature discussion, indicating how the current study contributes to existing knowledge and where it sits within that research
- the research methodology, the associated limitations for the study and how the first four research questions were addressed in Chapters 4, 5 and 6.

Next, the chapter presents a more developed discussion on how the study addressed the central research question. It then addresses the fifth research question by identifying recommendations for practice and suggestions for future research. The chapter concludes with a personal reflection on the research journey.

## 7.2. The research problem and questions

Three complicated issues formed the focus of this research. These are:

- adolescent mental health and wellbeing
- ‘disability’, and the inclusion of SEN students in high schools
- parent-school relationships

Each issue is of current concern to health and education professionals; each issue is the subject of national and state policy frameworks; and each issue has an extensive research history. Despite the focus and the policies and the research evidence, adolescent mental health problems are on the rise, understandings of disability are inconsistent, the practicalities of inclusion are unresolved, and parent-school relationships remain problematic. One group of SEN students, neurodiverse students, are more likely to develop mental health issues; they are less likely to be successfully included at school, indeed are less likely to be successful at school; and their parents are more likely to experience difficult relationships with educators (APA, 2013; Deloitte, 2017; Gwernan-Jones et al., 2015; Woodcock & Reupert, 2016). The vulnerabilities of these students, and the challenges their parents face, present as a significant and worthy research focus.

Apart from the significance of the research problem, the current study had three underlying (personal and professional) rationales: an interest in the wellbeing of neurodiverse children, an interest in inclusive high school environments, and an interest in the parent-school relationship. Consequently, the study aimed to develop a better understanding of the experiences of neurodiverse students in high school environments; of ways in which schools might effectively support and include these students; and how the parents of these students perceive their role in their child's education.

The central research question in this investigation aimed to discover *how the participants understood their neurodiverse child's experiences in high school settings, and their role in supporting their child's education.*

Five sub-questions guided the research. These were:

1. How did the participants describe and explain their child's experiences at school? This was addressed in Chapter 4.

2. How did the participants describe and explain their own experiences of supporting their child's education? This was addressed in Chapter 4.

3. How might the participants experiences be interpreted? This was addressed at the individual level in Chapter 5 and at the collective level in Chapter 6.

4. What principles, drawn from this interpretation, might contribute to current understandings of the inclusion of neurodiverse students, and of parent-school relationships? This was addressed in Chapter 6.

5. How might the study outcomes contribute to better support practices for neurodiverse students and more effective parent-school partnerships? This is addressed in Chapter 7.

A qualitative study, based on the principles of Interpretive Phenomenological Analysis (IPA), was designed to address these research questions. Five mothers of neurodiverse adolescents, who attended mainstream schools in regional and rural Queensland, participated in semi-structured interviews. A detailed examination of the data, with particular attention to the participants' use of conceptual metaphors, highlighted several important issues facing neurodiverse students and their parents. The participants expressed their concerns about aspects of the school context that they felt contributed to their child's anxiety, lowered wellbeing, and delayed their child's learning and schooling journeys. And they highlighted several aspects of the school context that they felt contributed to poor working relationships between schools and parents.

These issues, along with the challenges they pose for schools and parents, are discussed further in Section 7.5.

## 7.3. **The literature discussion and study contribution**

The literature discussion was organised according to an ecological systems perspective (Bronfenbrenner, 1977, 1986, 1992, 2001). It explored the lifeworlds of neurodiverse adolescents, and the lifeworlds of their parents, according to research into the reciprocal interactions between individuals and families, and the settings in which they live, learn, play, and work. The study discussion continued this focus on the social 'ecologies' of families and schools and examined the study findings through an ecological lens. This approach demonstrated that schools and families share a mutual responsibility for the wellbeing of neurodiverse adolescents.

The research discussion identified that there is national concern over the increase in mental health problems in young Australians (AIHW, 2018; ARACY, 2018; WHO, 2013). Consequently, student social-emotional wellbeing (SEWB) is a current focus for Australian health and education policies such as the *Australian Student Wellbeing Framework* (Education Council, 2018) and Queensland's *Student Learning and Wellbeing Framework* (Department of Education, 2018c). However, understanding the components of SEWB, particularly for neurodiverse students, is a work in progress.

Recent surveys into the mental health of young Australians indicate that school-related pressure is a major source of anxiety (ARACY, 2018; Bullot et al., 2017) but there is an identified gap in our understanding of what academic pressure looks like for young people (Aldridge & McChesney, 2018). A large body of research demonstrates that being engaged and successful at school is important for student wellbeing (ESA, 2018; MCRI, 2018b); and that neurodiverse students have an inherent risk for mental health disorders but also typically underperform at school, (Leitao et al., 2017; Storch et al, 2015; Wigham et al., 2017).

Positive, safe and supportive school environments are critical to all students' wellbeing (Mazzer & Rickwood, 2015; Slemp et al., 2017), and a sense of belonging and connectedness in the school community is especially important (Bowles & Scull, 2018). However, because neurodiverse students frequently experience social isolation or are unable to participate in mainstream learning activities (Deloitte, 2017; Robinson & Truscott, 2014), they are therefore highly vulnerable in school environments.

The current study:

- contributed to understandings about the specific challenges faced by neurodiverse students in high school settings. Many of these relate to what their parents perceive as the prioritising of academic achievement over social-emotional wellbeing, and pervasive expectations around post-secondary education.
- identified that, while academic and social belonging and connectedness are key dimensions of school-related SEWB, their relative affect is highly individual and dependent on student personal characteristics, family support, school culture and teacher capacity.

The most recent national surveys on SEN students acknowledge that there are inconsistencies in defining 'disability' in Australia, especially for Neurodevelopmental Disorders (Education Council, 2017). The issues around medical labels – whether they stigmatise or benefit – are complex and contested both in the research literature and in public discourse (Guerra et al., 2017; Rapp & Ginsburg, 2017). This confusion suggests the need for a better understanding of how medical labels are employed, in different educational contexts and across education authorities. There are also inconsistencies in defining ‘inclusion’ and in conceptualising the way students with complex and diverse needs should be included in mainstream schools (Anderson & Boyle, 2015; Department of Education, 2017). Given these inconsistencies, there is a further need to understand the experiences of neurodiverse students in mainstream classes. This is especially true in regional and rural Queensland schools, where teachers are often inexperienced, professional turnover is high, and medical, mental health and allied health service provision is limited (Halsey, 2018; Kuhl, Pagliano & Boon, 2015).

The current study:

- provided specific examples of inconsistent understandings of what constitutes ‘disability’, and inequitable inclusion provisions. It also demonstrated how parents of neurodiverse students perceive that they need to work around these limitations.

- contributed to the research on the schooling experiences of neurodiverse students in regional and rural Queensland and identified a perception, among parents, that the capacity of schools to successfully include neurodiverse children is compromised when teachers are inexperienced and do not have access to integrated teams of specialist support.

The research discussion established that the literature on parent-school relationships is extensive, and decades of research into educational contexts around the world demonstrates that effective parent-school partnerships promote positive learning and social-emotional outcomes for students (Emerson et al., 2012b). It is also well-established that effective parent-school partnerships and collaborations are difficult to achieve (Mapp, 2017). While there is support for the concept that ‘parent involvement’ and ‘parent engagement’ represent a continuum of interest and effort (Auerbach, 2007; Goodall & Montgomery, 2014), these terms are used inconsistently and interchangeably in the literature and in policy to describe the ways parents participate in schools and support their child's education (Stefanski et al., 2016).

The current study:

- contributed to the research in parent-school relationships by clarifying what 'involvement' and 'engagement' looked like for the participants and by identifying specific parenting behaviours associated with each construct.

Involving parents in their children's schooling and encouraging parents to be engaged in their children's learning are prioritised in national and state education policies (Department of Education, 2013; DEWR, 2017;). Parent-engagement frameworks, worldwide, identify mutual respect for parent and professional expertise, a welcoming school culture, and clear and bi-lateral channels of communication as essential elements of effective parent-school relationships. However, it is equally well-established that there is a practice-policy dissonance (Deloitte, 2017; Emerson et al, 2012b; Hornby & Blackwell, 2018), and that such relationships are difficult to achieve. Existing research suggests that this is particularly true for parents of neurodiverse children, who often have a problematic relationship with educators (Gwernan-Jones et al., 2015; Norwich et al., 2005; Reupert et al., 2015).

The current study:

- illustrated specific aspects of the local context that presented as barriers to parent-school partnerships. The study found that Queensland's existing system of verification prevented the participants' children from being able to participate on the same basis as their peers. The study also showed that it excluded the parents of those students who were ineligible for an IEP.

- supported evidence of the policy-practice gap. The participants described feeling excluded, ignored and frequently belittled by education professionals and perceived that their efforts to support their child were interpreted as over-involvement and 'helicopter' parenting.

- demonstrated that the participants' engagement and involvement behaviours were proportionate to the degree of anxiety they felt about their neurodiverse child's wellbeing and wellbecoming.

The research discussion identified that there is a growing body of literature which aims to understand the lived experiences of parents of children with disabilities from their own perspectives (Lalvani, 2011, 2015), and at an individual level (Kamenopoulou, 2016); the current study adds to this body of literature.

Finally, there is a growing number of researchers who straddle the worlds of academia and parenting 'differently abled' children (Good et al., 2017; Rapp & Ginsburg, 2001, 2017; Ryan & Runswick-Cole, 2008). As such they are outsiders to the world of disability but insiders to the world of disability support and the stigma attached to parenting children with 'disabilities'. My own experience in the worlds of education and academic research, and as the mother of a neurodiverse child, confirms that the current study sits within this body of literature.

## 7.4. **Reflections on the research methodology**

Interpretive Phenomenological Analysis (IPA) (Smith, 1996, 2004; Smith et al., 2009) is a phenomenological, interpretive and idiographic approach to social research and asks, 'what is this experience like for this person?' from the perspectives of both participant and researcher. IPA analyses identify recurrent themes across participants' lived experiences but also focus on the meaning of an experience for each participant on an individual basis (Smith, 2011; Smith et al., 2009).

The chosen methodology of IPA permitted a detailed exploration of the experiences of the five mothers who participated in the current study, and provided a way to closely examine two related phenomena: the ways parents perceive their neurodiverse adolescents' interactions in school social, learning and physical environments; and the ways parents subjectively experience their own interactions with individuals in their child's educational contexts.

IPA allowed for an idiographic emphasis that gave the participants a voice as co-researchers in the current study. Their stories were presented in their own words, although abridged, in Chapter 4. The participants' narratives took the place of the transcript extracts that usually serve to illustrate the researcher's interpretation and provide evidence for the researcher's claims. In the current study, it was felt that the narratives more effectively captured these mothers' lived experiences and allowed the reader to make their own assessment of how the participants described their child's experiences at school, and how they described and interpreted their own experiences of participating in their child's education.

IPA allowed for new insights into the lived experiences of neurodiverse adolescents and their parents through the researcher's interpretation of the participants' narratives presented in Chapter 5. These were interpreted via the key conceptual metaphors through which each mother understood and explained her lived experience. These conceptual metaphors also provided a unifying framework for the key themes that emerged from analysis of each mother's narrative. Each mother's conceptual metaphors provided a window into the participants' lifeworlds and sense-making activities and, in this respect, captured the essence of the central phenomenon – the parent-school relationship – for each mother

Finally, IPA allowed for an explanatory connection to be made between these stories, the researcher's interpretations and existing research. Chapter 6 synthesised the themes and metaphor 'families' that recurred across the participants' narratives into three collective narratives that illuminated the combined essence of these mothers' experiences. The chapter related these collective narratives to the extant literature, and developed a set of principles around better support practices for neurodiverse students and more effective parent-school partnerships.

### 7.4.1. Reflections on IPA, sample size and homogeneity

These findings illuminated the experiences of five mothers, whose neurodiverse children attended schools in rural and regional Queensland towns. Furthermore, the participants were educated, middle-class and highly motivated – they had the financial and social capital to support their child's education. As with other IPA studies, the participants' experiences are 'uniquely embodied, situated and perspectival' (Smith et al., 2009, p. 29). However, the study also illustrated the phenomenological, *being-in-the-world* aspects of the participants' experiences – their relationships with other family members, other parents, and with educational, medical, mental and allied health professionals. Through descriptions of the participants' parenting behaviours, the study illustrated their relationships with social constructions of 'good parenting'. Thus, the study findings offer both unique and relational perspectives of the phenomena of parent-school relationships.

The recruitment strategy of snowball sampling, and the fact that several of the participants were known to the researcher through schools and parent support groups may have been limiting factors. Future research into the experiences of parents of neurodiverse children could benefit from a different research design that allowed for a larger, more diverse population. However, in the current study, the sampling strategy and element of familiarity are both appropriate to IPA research, and allowed for depth and richness in the data.

### 7.4.2. Reflections on IPA, data collection and analysis

Chapter 3 ended with a discussion on demonstrating credibility in the research design and process. I found, with such an 'open-ended' methodology as IPA, that this was complicated by the way the data were collected and the way in which they were analysed. Inviting each participant, at the start of their interview, to discuss their lived experiences of parenting a neurodiverse child resulted in a mass of seemingly unrelated data. On re-reading the transcripts, much of this was due to researcher inexperience with interviewing, and the confusion of how to proceed when the participants unexpectedly changed the interview direction. Certainly, follow-up questions could have been more targeted. Sifting through these data for convergent themes, whilst resisting the temptation to impose external theories or principles, was an intensely time-consuming process. I ended up developing multiple thematic schemas for each participant, and then across participants, before I was able to see a coherent 'picture' of the phenomenon. There are no shortcuts to learning how to 'do' IPA other than to actually 'do' it; I tried software programs such as NVivo but found that this took me too far away from the data. Whilst the process of mapping the participants' use of conceptual metaphors was slow, it provided a meaningful way of achieving coherence.

In Chapter 3, I also noted that achieving a plausible depiction of the central phenomenon in an IPA study depended on the congruence between the researcher's interpretation and the researcher's skill in communicating this to the reader. All phenomenological studies rely on an iterative interpretive and writing process and, whilst I feel that the end result conveys these mothers' lived experience, this also proved to be an elusive goal and a difficult stage in the current study. That said, by the end of these processes I felt that I had a strong understanding of the participants' lifeworlds.

## 7.5. **Addressing the central research question**

In this study, the participants perceived that the wellbeing of their neurodiverse child depended on a sense of belonging and connectedness in school learning and social environments. They also felt it depended on the support of family at home and parental intervention at school (Figure 7.1). While the study supports existing research into school-related SEWB, its key contribution lies in illustrating the interrelatedness of these factors and the ways in which these parents supported their neurodiverse child's wellbeing. Additionally, in providing rich detail about the lived experiences of five neurodiverse adolescents and their mothers, this study emphasised the interdependence of student and parent wellbeing.

The participants acknowledged that their neurodiverse children were surviving, although not necessarily thriving, at school because of their own determined support efforts. However, despite their sense of responsibility, these mothers felt unsupported and lacking in the appropriate skill set. The participants' sense of parent-efficacy and wellbeing was affected by their ability to access authoritative information around their child's issues, their ability to access appropriate medical, mental health and allied health services, and their sense of belonging and connectedness in the school community. In turn, these factors affected their capacity to support their child's learning and schooling journeys (Figure 7.1).

In addressing the central research question, the interdependent factors affecting student and parent wellbeing are explored below. Section 7.4.1 addresses the first part of the central research question: *'How did the participants understand their neurodiverse child's experiences in high school settings?'*. Section 7.4.2 addresses the second part of the central research question: *'How did the participants understand their role in supporting their child's education?'*.

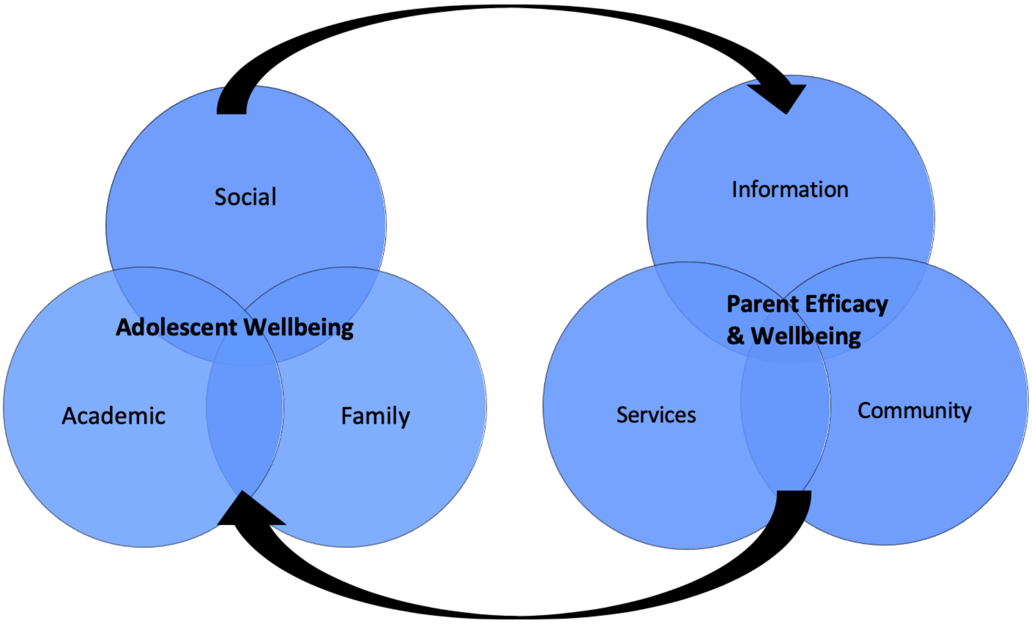

*Figure 7.1* The interdependence of student and parent wellbeing

### 7.5.1. Part 1. The experiences of neurodiverse students

In this study, the participants' use of conceptual metaphor was taken to illustrate their way of thinking about lived experience, and their way of seeing the world. In Chapter 6, the metaphor 'families' that together made Collective Narrative One: *The Learning Journey*, provided insights into how the participants understood their neurodiverse child's experiences in high school settings. These insights supplied evidence for an ecological perspective on adolescent anxiety and highlighted new perspectives on several issues:

- Belonging and connectedness at school are known to be problematic for neurodiverse students. However, this study emphasised how these constructs were affected by the very individual way the participants' children experienced academic and social pressure.

- For some time, educators and parents have raised concerns about the negative impacts of 'testing cultures'. The study contributed to this debate by highlighting how the participants' children perceived this as pressure – to achieve at school, to attain a 'good' OP, and to have a decided post-secondary pathway. The participants read this as prioritising academic achievement over social-emotional wellbeing.

- While it is well-established that 'doing' inclusion is problematic, especially at high school, the study highlighted how current disability provisions, certain classroom environments, and mainstream academic and social expectations do not support the developmental needs of neurodiverse students.

From these insights, two principles of supportive school environments that enable participation by neurodiverse children were drawn from Collective Narrative One. These principles capture the ways the participants believe schools can address the wellbeing of neurodiverse students. They suggest that schools must:

1. Create developmentally appropriate school environments
2. Ensure an equal focus on social, emotional and academic competencies

These principles are explored below, in terms of the challenges and possibilities they pose to schools as they seek to support neurodiverse students in high school settings. The implications of these challenges are explored below in Recommendations for Practice (Section 7.6) and Suggestions for Future Research (Section 7.7).

#### 7.5.1.1. Developmentally appropriate school environments

***Key Principle 1***

***Create developmentally appropriate school environments***

While the study participants acknowledged that anxiety was a component of their child's Neurodevelopmental Disorder, they identified specific environments in which this anxiety manifested itself. Overwhelmingly, these were the aspects of the school environment in which these neurodiverse adolescents were least able to participate and that made them feel most conspicuously different to their peers. The participants believed that mainstream school contexts are organised around the needs of developmentally typical students and that neurodiverse students are disadvantaged because:

- There may be a poor fit between the students' attentional issues and the pace of instruction – students with ASD or ADHD wanted to work in-depth on specific tasks that held their interest.
- There may be a poor fit between the students' comprehension of social cues and their capacity to fit into peer social or learning groups.
- There may be a poor fit between these students' level of impulse control and their capacity to follow classroom instructions or work with peers.
- There is usually a poor fit between the students' capacity to complete learning tasks and the general pace of instruction.
- There is usually a poor fit between the students' capacity to retain information and the number of learning instructions issued.

These observations provide an ecological explanation for these neurodiverse children's anxiety. That is, the participants perceived a poor fit between high school settings, high school pedagogies, and their child's specific learning and social-emotional needs. Caring for the wellbeing of neurodiverse students, therefore, requires developmentally appropriate school environments that:

- Acknowledge the strengths and weaknesses associated with Neurodevelopmental Disorders, while meeting individual students ′ needs.
- Support teachers to include neurodiverse students

### Acknowledging the strengths and challenges of neurodiversity – one student at a time

Chapter 1 explained why the current study has described the participants' children as being 'neurodiverse'. However, this umbrella term, whilst removing some of the negativity associated with 'disorders' and 'disabilities', also signals the difficulties of successfully including neurodiverse students without a clear understanding of their individual needs.

The study demonstrated that creating developmentally appropriate school environments that meet individual students' needs is made significantly more difficult by the broader issues around defining disability in Queensland schools. Potential challenges for schools include:

- Providing adequate support for students or teachers without a comprehensive knowledge of Neurodevelopmental Disorders
- Providing adequate support for students or teachers when a student's diagnosis is not a recognised disability
- Avoiding the pitfalls of stereotyping students according to their diagnosis
- Understanding the implications of overlapping diagnoses
- Understanding individual neurodiverse students' specific challenges and strengths
- The need to celebrate the strengths of neurocognitive difference whilst appreciating the reality, and circumstances, of an individual's 'disability'

These issues were highlighted by the participants' flexible and pragmatic approach to their child's diagnosis and 'disability' label. Chapter 6 described how these mothers employed a medical or deficit approach when it permitted their children to obtain whatever classroom support that a verifiable disability diagnosis would confer, recruiting the support of medical professionals where possible. At the same time, the participants explained their children's academic failure or social isolation through a social model of disability that focussed on the barriers to participation presented by mainstream environments.

The study concluded that these mothers' pragmatic attitudes towards the label of 'disability' arose from their need to negotiate existing and inflexible support provisions in schools and to ensure their child's inclusion. The participants felt that inclusion practices should be based on individual need rather than diagnostic criteria – even when their children's teachers knew 'something was not right', their capacity to include was hampered by the existing requirements around verification within Queensland's EAP. The participants saw these as a barrier to equal access to education for all students and felt that, without an 'accepted' diagnosis, the additional needs of neurodiverse students go unrecognised and unsupported.

The participants' experiences confirmed Farrugia's (2009) suggestion that educator resistance to a child's inclusion can be countered by more 'legitimate professional power' (p. 1024). In their case, it was a paediatrician's advice, and the diagnosis required for an IEP that provided the necessary professional 'firepower' to ensure support and respect for parental concerns. There are issues of social equity if a child's inclusion relies on a parent's ability to access timely and authoritative professional support, rather than apparent need.

### Supporting teachers to include neurodiverse students

Although the participants believed mainstream high school teachers regularly made inaccurate assumptions about their neurodiverse children, they stressed that teachers were inadequately supported in terms of education around neurodiversity and classroom assistance. The participants identified that:

- Teachers lacked professional knowledge of the learning and social-emotional needs of neurodiverse students.

- Schools were understaffed with either school psychologists or Guidance Officers. They noted the significant time lag between their child's class teacher flagging a problem and professional assessment or advice.

- Learning Support teachers were overburdened. They commented on these teachers' case load and questioned how they could possibly address the needs of every student who required support.

- Class size *does* matter. The participants felt that their child's 'invisible disability' became even less visible to teachers responsible for large and diverse classes. They also noted that their child's sensory issues were exacerbated in large and noisy classes. Because of the issues with social comparison, they felt that their child's anxiety was lessened when they worked in smaller groups of students with similar abilities.

#### 7.5.1.2. Understanding academic and social pressure

***Key Principle 2***

***Ensure an equal focus on social, emotional and academic competencies***

This study illustrated how intense academic and social pressure were everyday experiences for the participants' neurodiverse children and presented significant challenges to their overall wellbeing. The pressure to achieve, and to fit in, negatively impacted their mental and physical health.

Although these adolescents had a demonstrated capacity to achieve – cognitive assessments indicated their intelligence was equal to, or higher than their peers – their learning differences, and the way they were included in mainstream classes, resulted in academic underachievement. Their inability to achieve, independently and relative to peers, caused a perception of intense academic pressure that eroded their confidence at school and resulted in chronic anxiety.

The participants observed that their children experienced academic pressure as a general need to 'keep up' in high school, and as an expectation that they should fit into existing mainstream classes with minimal adjustments or support. There was a strong perception, among the participants, that high school educators were overly focussed on academic outcomes at the expense of their children's social-emotional wellbeing. They attributed this to external pressure on teachers to meet educational goals that resulted in a constant and excessive emphasis on assessment and academic achievement. They felt that schools had a narrow focus on OP results and tertiary education that excluded their children. Moreover, they felt that teachers' 'capacity to care' was affected as a result.

The participants also discussed specific ways in which academic pressure was experienced by their children and identified:

- the focus on independent learning in high school that becomes problematic when a student lacks executive functioning skills
- the focus on literacy, in all subjects, that obscures a student's other abilities
- the emphasis on preparing for standardised testing (such as NAPLAN) and the importance placed on the results of those tests.
- the priority given to wellbecoming, that is, to the students' *future* prospects over their *current* sense of belonging and safety at school. The participants observed that, at high school, there is a constant forward-looking focus on post-secondary education. That focus prioritises a university education, and, especially at competitive independent schools, gaining a place at a prestigious university.

The participants observed that the academic pressure experienced by their child was compounded by their conflicting needs for support and autonomy and that this resulted in a perception of intense social pressure. These students required comprehensive adjustments to, and assistance with, instruction, learning activities and assessment tasks. At the same time, they wanted to work independently and not stand out from their peers. Even when the child had well-developed social skills and strong friendships, they perceived a stigma associated with being different, and experienced considerable anxiety when they did not fit in. There was an added burden when the child's primary diagnosis related to ADHD and ASD. In these cases the participants observed that teachers frequently held unrealistic expectations around social skills and classroom behaviours, that there was a general lack of understanding about Neurodevelopmental Disorders, and that their child was expected to fit into the school's existing social structures, such as playground friendship groups, with limited support. All these adolescents belonged to sporting and social clubs, had holiday or part-time jobs and demonstrated a capacity for sustained friendships. In other words, they enjoyed socialising to varying degrees. However, school peer groups presented different social challenges. Whether this was related to personal characteristics typical to ASD or ADHD, or the fear of being seen as different, these adolescents were caught in a difficult cycle. They experienced actual academic or social challenges, self-stigmatised themselves as awkward or 'dumb', and had their perceptions reinforced by their peers or by inconsistent reactions from teachers.

### 7.5.2. Part 2. The participants' perceived role in their child's education

In Chapter 6, the metaphor 'families' that generated the collective narratives of *Helping Them Get to the Other Side* and *Falling on Deaf Ears* provided insights into parent-school relationships and how the participants perceived their role in their child's education. These narratives identified the:

- Critical role families play in supporting their neurodiverse child
- Important differences between 'parent engagement' and 'parent involvement'

The narratives also identified an urgent need to support families as they support their neurodiverse child through:

- Access to authoritative information and services
- Consensus on 'appropriate' levels of parent involvement and shared responsibility
- Systems of home-school communication that meet families' needs

The study found that, for these mothers, the parent-school relationship was affected by their justifiable concerns over their child's wellbeing and wellbecoming. The uncertainties around the recognition of Neurodevelopmental Disorders in Queensland schools, and professional experience with, and attitudes to, neurodiversity discussed above caused the participants to question the capacity of teachers to include their neurodiverse child. Consequently, they perceived their parental role as safeguarding their child's current and future wellbeing. While the participants were highly engaged in their child's broader education at home, they perceived limited opportunities to be involved in their child's school in a meaningful way. They perceived that schools did not value their parent knowledge, were unwilling to acknowledge their concerns, and were unwilling to include parents in decision-making processes. Although these presented as significant barriers to successful parent-school partnerships, they made the participants more determined to 'find a way in' to their child's school. All of the above had significant impacts on the quality of parent-school interactions.

The study concluded that the relationship between schools and these parents of neurodiverse children was characterised by poor communication and mutual mistrust. It also concluded that these parents shouldered an overwhelming burden of responsibility for their child's wellbeing and wellbecoming that could have been relieved by authoritative advice and guidance.

From these insights, five principles of effective parent-school partnerships were drawn from Collective Narratives Two and Three. The principles capture the ways in which the participants believed that schools could address the identified barriers to parent-school partnerships. They suggest schools must:

1. Create welcoming settings that encourage parents to share how they support their child's learning and schooling journeys.
2. Empower and support parents by providing authoritative advice and access to coordinated services.
3. Attend to parents' reasons for being engaged and being involved
4. Consult with parents around the development of guidelines for parent participation.
5. Involve parents in, and inform them of, the decision-making processes relating to their child's inclusion.

These principles are explored below, in terms of the challenges and possibilities they pose to schools and parents as they seek to develop working partnerships to support neurodiverse students. The implications of these challenges and possibilities are explored below in Recommendations for Practice (Section 7.6) and Future Research Possibilities (Section 7.8).

#### 7.5.2.1. ‘Parent engagement’ versus ‘parent involvement’

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***Key Principle 3***

***Encourage parents to share how they support their child’s learning and schooling journeys***

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The study highlighted the participants’ beliefs that educators and school leaders were unaware of the complexity of their parenting experience and the ways in which they supported their child’s learning and schooling journeys. The study identified specific parenting activities that were associated with ‘parent engagement’ and ‘parent involvement’.

‘Parent engagement’ was found to encompass the mothers’ efforts to promote and manage their child’s cognitive and social-emotional development at home. This included organising outside-school academic tuition and ‘enrichment activities’ such as music and sport. It also involved coordinating medical, mental health and allied health appointments and assessments and overseeing follow-up exercises and programs. And it involved developing a ‘para-professional’ understanding of their child’s needs.

‘Parent involvement’ encompassed the mothers’ efforts to supervise their child’s schooling journey. This included communicating concerns around their child’s issues to educators to a degree that amounted to supervision; liaising between school and other professional services; and advocating for their child’s inclusion at school.

This study concluded that while ‘parent engagement’ and ‘parent involvement’ are separate constructs, both are forms of a caring effort and are motivated by what these mothers perceived as their ‘mothering responsibilities’ and ‘care-ful’ concern for their child’s wellbeing. However, they felt that schools clearly differentiated between the spheres of home and school and conveyed the message that parents should prioritise efforts at home and confine their efforts at school to specified and restricted activities.

The study determined that, from the perspective of these participants, effective parent-school partnerships allow parents into ‘teacher spaces’ to assist teachers to support neurodiverse students; and to assist parents to support their child’s education in a way that responds to individual family needs. They give parents opportunities to explain how they support their child’s education at home, and how they wish to see their child supported at school.

#### 7.5.2.2. Access to services and authoritative information

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***Key Principle 4***

***Empower and support parents by providing authoritative advice and access to coordinated services***

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The study interpreted the participants’ engagement and involvement activities as an attempt to create the type of ‘advantaged and stable’ home and school environments that Bronfenbrenner and Ceci (1994) suggested would promote positive developmental outcomes (p.577), thus counteracting the disadvantages experienced by neurodiverse children. They were hindered in these efforts by significant difficulties with access to, and continuity between, specialist medical, mental health and allied health services. The study also found that, despite the availability of extensive online support services, the participants struggled to find authoritative information, trusting in word of mouth recommendations and the support of other parents.

The study identified that access to services depended on the family’s address, social and financial capital. The mothers observed that government medical, mental health and allied health services in regional and rural Queensland are limited and overstretched; in several cases their children missed out on timely diagnoses and interventions as a result. And they identified a lack of interdisciplinary services, which ensure continuity and coordination of care, in the government sector.

The mothers’ difficulty in accessing and coordinating appropriate support, and advocating within medical and education systems for their child, is a recognised issue (Cologon, 2013; de Boer et al., 2011; Mitchell et al., 2010; Tretault, Freeman, Carriere, Beaupre & Deschenes, 2014). However, the current study illuminated these issues in a detailed manner and highlighted the specific problems for families in regional and rural Queensland. The participants’ experiences provide personal examples of the issues that Warren (2018) identified around the availability of health services for children in regional and remote areas.

The study identified a need for more consistent access to, continuity within and communication between, services. This included Guidance Officers and Learning Support teachers as well as visiting allied health professionals. Models of ‘coordinated care’ exist within health and mental health systems, yet coordination between government health and education systems only appeared to be open to parents of SEN students with verifications. Two participants who were able to dedicate personal and financial resources to accessing an integrated team of professionals had better educational and social-emotional outcomes for their children. However, this was costly, only available in Brisbane and involved a lengthy waiting period. The other participants were confronted with coordinating their child’s interrelated diagnoses and educational needs with inadequate or no support.

The participants’ efforts were also hindered by uncertainty around authoritative sources of information and evidence-based interventions. They described a steep learning curve in attempting to understand their neurodiverse child, and in providing appropriate support, that they felt was beyond their skill set. The participants emphasised the positive contribution the ‘right’ professional – paediatrician, speech pathologist, psychologist or teacher – had made to their lives and expressed their sense of relief in being able to ‘hand over’ an aspect of their ‘mothering responsibilities’.

Although they acknowledged the value of professional advice, the participants actively cultivated personal social networks for support and information. An absence of professional advice and guidance, especially in regional and rural areas, sent parents in unconventional directions that were often expensive and not always helpful. They noted that often the only staff member with authoritative knowledge of neurodiversity was the school Guidance Officer or Learning Support teacher and the participants felt that these educators were already stretched by the extent of their role and number of children needing support.

The study demonstrated that, in the absence of coordinated educational, medical, mental health and allied health services, participants perceived no options other than to 'manage' their child's diagnosis and interventions. However, caring for their neurodiverse child had a significant, and often negative, impact on the participants' wellbeing – they all described feeling exhausted and frequently overwhelmed by their 'mothering responsibilities'.

While parents play a critical role in supporting their child's mental health and wellbeing, the current study found critical gaps in service provision and the participants' mental health literacy. The participants' experiences supported Reupert and colleague's (2015) call for schools to act as 'catalyst points' for information and coordination of services; in part to alleviate the loneliness of their support role and in part to ensure appropriate and timely advice. Ensuring the wellbeing of neurodiverse students therefore involves supporting parents' efforts to support their child through and authoritative advice and access to coordinated services.

#### 7.5.2.3. Motivations for parent involvement at school

***Key Principle 5***

***Attend to parents' reasons for being engaged and being involved***

This study highlighted that schools must appreciate parents' motivations for being highly involved at school and understand the balance parents are trying to achieve. In this way, the study responds to an identified need for further research into the reasons why parents engage in intensive parenting or 'helicopter parenting' behaviours (Padilla-Walker et al., 2019).

Studies into over-involvement (Nelson, 2010; Segrin et al., 2015) generally look at the issue from the perspective of parent desire to create advantage for their child in a highly competitive world. Such studies tend to examine the motivations of parents of university-eligible students. Fewer studies are concerned with understanding why parents of neurodiverse students, who are at risk of not completing school, feel the need to be highly involved in their child's education.

The current study illustrated that the participants' efforts to create 'advantaged and stable' environments at home and school were related to the degree of anxiety they felt for their child and their perceived need to compensate for deficits in the school environment. For these mothers, their rationale for being highly engaged at home and highly involved at school was to *reduce disadvantage* for their child and 'level the playing field'. They explained that their efforts were not intended to deliberately create *advantage over* other children, which is frequently cited as a reason for 'overinvolved' parenting behaviours.

The participants understood the consequences of being overly involved but they were also trying to cope with their child's evident distress and anxiety at home. Behaviours that schools might have interpreted as overly concerned and overly persistent came from a place of parental love and care. More importantly, they evolved from a sense of being kept at a distance.

The current study supports research which identifies relational trust as the foundation for effective and productive parent-school partnerships. The participants' level of involvement depended on the degree of trust they had in the school. This was conditional on the degree to which they felt their child was included and cared for at school, and the degree to which the participants felt included in the decision-making process for their child's education.

The study highlighted that these mothers started from a position of tacit trust in the school as an institution; their acceptance of the divide between home and school was evident in their reluctance to intrude in the 'work of the school'. While they did not want to be 'up at the school' all the time, they felt a need to supervise their child's schooling to pre-empt negative outcomes for their child when their learning, social or behavioural needs were not accommodated.

Trust was also conditional on the way their child's issues and progress were communicated to the participants, and on their ability to communicate with educators and leaders. They commented that, unless, their child had a verified disability and an IEP, there were few options open to them in terms of being involved or communicating with their child's teachers. When emails went unanswered or requests for help were ignored, these parents felt they had no option other than to ‘intrude’ – in terms of persistent contact or physical presence – into ‘teacher spaces’. This adds to understandings of relational trust by highlighting how policies designed to support and include students with disabilities can have the effect of alienating, and causing mistrust among, those parents whose children have the ‘wrong’ disability.

The study highlighted that trust was also a factor in these parents’ efforts to advocate for their child. They felt their parent knowledge and expertise made them the most logical advocates for their child; and that if they did not advocate, their child would be overlooked and not included. A key aspect of the mothers’ advocacy efforts was therefore orientated towards making their child’s ‘invisible’ disability visible to classroom teachers and school leaders. However, the participants identified systemic barriers in high schools that prevented their voice from being heard and made them feel as though they had to ‘fight’ for their child’s inclusion. Consequently, when they were most actively advocating for their child, their relationship with the school was at its lowest point.

Material and social resources enable parents to advocate more effectively for their child (Lalvani, 2012), and these factors were borne out in the experiences of the parents in the current study. The ways in which each mother advocated for her child depended on personal circumstances such as financial and social capital and the extent of their social support network. Even with close family support or social networks, a significant aspect of these mothers’ advocacy experiences was their strong sense of being alone. Their advocacy efforts were largely unsupported by parent or disability advocacy groups. This may have been connected to their perceptions of what constituted a ‘disability’, or it may have been related to their strong sense of the stigma attached to being overinvolved or ‘helicopter mothers’.

Ryan and Runswick-Cole (2008) suggest that advocacy is an aspect of the mothering role for mothers of children with disabilities, and also, that advocacy frequently extends into activism for these mothers. The participants were interested in exploring ways to share their lived experiences with other parents as a form of solidarity and mutual support. They were also interested in exploring ways to share their lived experiences with educators as a means to effect positive changes for neurodiverse students and their families.

However, although the mothers hoped that others might benefit from their experience, and hoped-for change in existing systems, their main focus was on their own child's wellbeing and their efforts lacked the coordination and systemic support that characterise activism.

#### 7.5.2.4. 'Appropriate' levels of parent involvement at school

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***Key Principle 6***

***Consult with parents around the development of guidelines for parent participation***

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Most studies on parent engagement and involvement, and the policies that evolve from such research, are concerned with understanding how to encourage involvement from largely disengaged parent populations such as ethnic minorities; parents with low education or SES levels; or Indigenous families. The current study identified that encouraging these mothers to become involved was not the issue. However, they expressed uncertainty around what schools considered as an 'appropriate' level of parent involvement. The study found that there was limited agreement on, or clarification around the level and type of involvement expected or appreciated by their children's schools. This was especially true for the participants whose children did not have a verification.

The participants' experiences illustrated that, other than in ways that serve the school community, schools are ambiguous and inconsistent about how they wish parents to be involved. Because of this, the participants held ambivalent attitudes to being highly involved at school, seeing it as a regrettable necessity in the absence of clearly communicated protocols, and feeling negatively judged as being over-involved in their child's life.

21st century constructions of what it means to be a 'good' mother appear to be open to numerous interpretations (Miller, 2017; Mortimer & Larson, 2002; Sorin & Galloway, 2006) and mothers of neurodiverse children already struggle with the stigma of being publicly scrutinised and blamed for their parenting (Farrugia, 2009; Francis, 2012; Vincent, 2017). There are similarities between the study participants' experiences of stigma and those described in the research. However, as a group, the participants perceived that negative judgements about their parenting were related to being overly involved in their child's life and a perception that they were unwilling to let their child make mistakes or fail. They consciously used the expression 'helicopter mother' to denote both their level of involvement and the way educators and other parents perceived their parenting behaviours.

There was a general perception that these judgements were unfair. Even though the mothers expressed conflicting views about their highly involved parenting, they believed their child had only 'survived' at school due to their management, supervision and advocacy. On the one hand, they understood and tacitly agreed with public and professional discourses around 'helicopter parenting' and prefaced their discussions by stating that they did not want to be seen as a 'helicopter mothers'. On the other hand, these mothers defiantly rationalised being a 'helicopter mother' in terms of their additionally complex caring and mothering responsibilities. They emphasised that this role would be redundant in the eventuality of effective systems of parent-school communication, and respect for parent knowledge.

Farrugia (2009) noted the 'active disclosure of otherness' by a group of parents of children with ASD as a means of controlling knowledge about their child and their own parenting (p.1024). In the current study, it appears that these mothers were reappropriating the term 'helicopter mother' to describe behaviours consistent with their 'mothering responsibilities' and with their concept of how 'good mothers' behave. However, they were still highly aware of the negative and judgemental attitudes associated with this term. They were indignant that what they saw as responsible, caring parenting was interpreted as being overly anxious and controlling. The study identified this as a key issue for these parents' sense of belonging in the wider school community.

The current study found that these ambivalent attitudes can be at least partly attributed to imprecisely defined parameters for parent involvement in school. The participants' experiences demonstrated the need for a tailored approach to collaborating with parents based on understanding their specific reasons for being involved at school.

#### 7.5.2.5. The concept of shared responsibility

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***Key Principle 7***

***Involve parents in, and inform them of, the decision-making processes relating to their child's inclusion***

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The study highlighted that the participants had all felt excluded from decisions around their child's education, that their parent-knowledge was not valued, and that their concerns had been ignored, over considerable periods of time. But they also explained that an inclusive and open professional attitude towards their experience and parent knowledge contributed significantly towards their good-will.

Despite the existence of national and state parent-engagement frameworks, the study supports existing research suggesting that schools do not always admit to the concept of shared responsibility for the child's wellbeing by including parents in decision-making processes (Weiss et al., 2010) or acknowledging parent knowledge and expertise (Pushor, 2017; Pushor & Ruitenberg, 2005).

Australian research indicates that teachers feel unprepared for parent participation in schools (Doecke et al., 2008; Saltmarsh et al.,2015) and the mothers in the current study believed that, not only were educators and school leaders uncomfortable with the idea of sharing responsibility, but hid behind their professional knowledge and used 'teacher speak' or esoteric language to distance parents and 'put them in their place'.

Effective home-school communication is acknowledged as a foundational aspect of effective parent-school partnerships in federal and state parent engagement frameworks (DEEWR, 2017; Department of Education, 2013). However, the current study indicated that issues around home-school communication functioned as significant systemic barriers to effective parent-school partnerships and adversely affected the participants' relationship with their child's school.

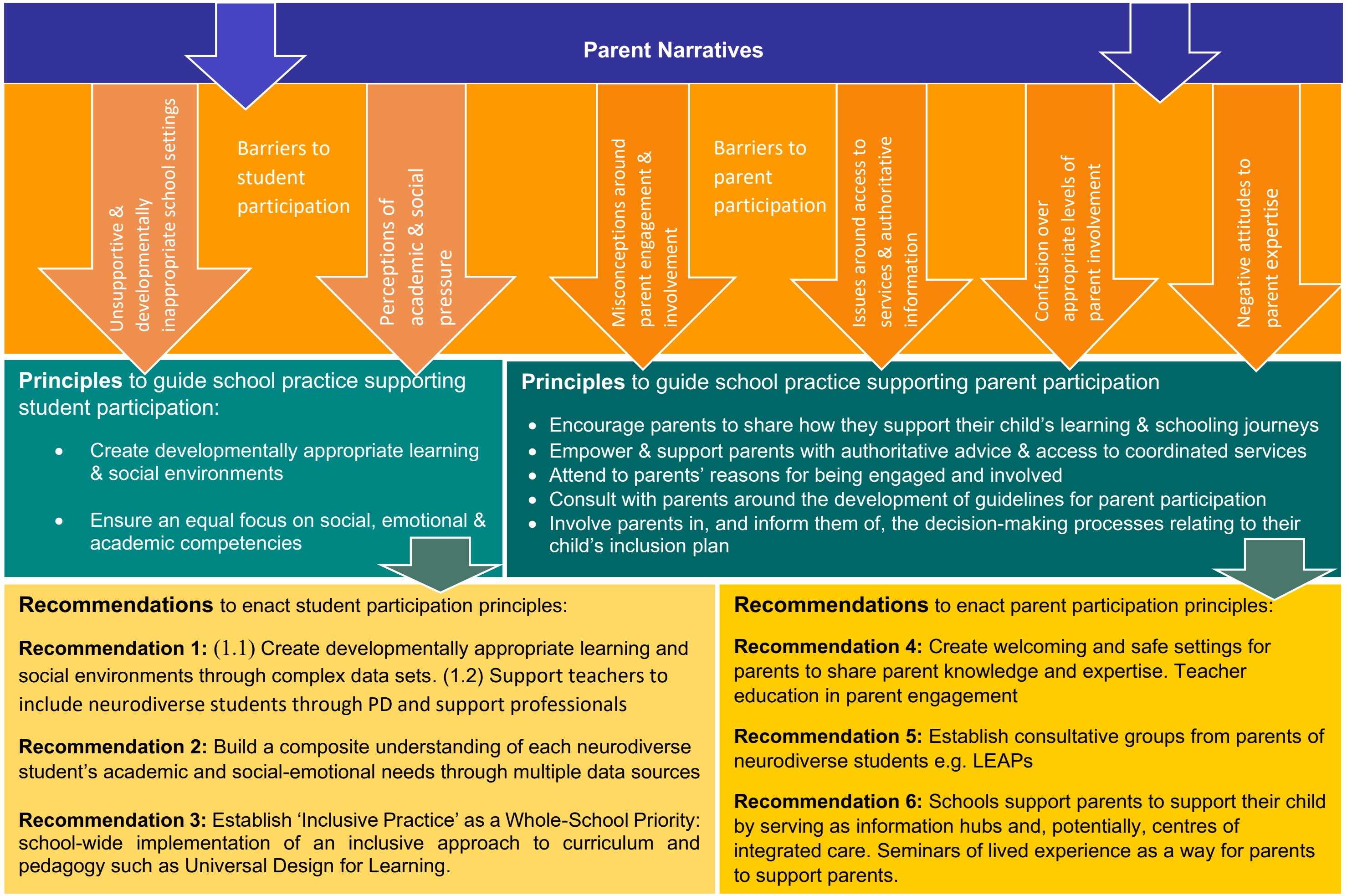
The participants identified that communicating their parent knowledge and expertise was a significant motivator for being involved in their child's school. While they saw teachers as overburdened and were reluctant to be seen as the source of further stress, their priority was to ensure that their child was a fully participating and accepted member of the class community. However, they explained that systemic issues around home-school communication and dismissive attitudes to parent knowledge made them feel powerless and frustrated in their interactions with educators.

## 7.6. Recommendations for practice

Ensuring that all students feel safe, supported, and connected at school is an underlining principle of Australian education policy and professional standards. Consequently, removing barriers to social and academic belonging should be, and generally is, part of every school's vision for teaching and learning. So too is establishing respectful relationships with parents and community. However, this study suggests that the rhetoric of inclusion is still far from being a reality for neurodiverse students and their parents.

Improving the wellbeing of neurodiverse adolescents and including and supporting their parents require a long-term and sustained commitment to increasing public and professional awareness of the implications of Neurodevelopmental Disorders, and to breaking down barriers between schools and families.

In the short term, there are actions, that schools can take, to remove barriers to participation for neurodiverse students and their families. Recommendations for practice in these areas are summarised in Figure 7.2 and explored below.



**Principles** to guide school practice supporting student participation:

- Create developmentally appropriate learning & social environments
- Ensure an equal focus on social, emotional & academic competencies

**Principles** to guide school practice supporting parent participation

- Encourage parents to share how they support their child's learning & schooling journeys
- Empower & support parents with authoritative advice & access to coordinated services
- Attend to parents' reasons for being engaged and involved
- Consult with parents around the development of guidelines for parent participation
- Involve parents in, and inform them of, the decision-making processes relating to their child's inclusion plan

**Recommendations** to enact student participation principles:

**Recommendation 1:** (1.1) Create developmentally appropriate learning and social environments through complex data sets. (1.2) Support teachers to include neurodiverse students through PD and support professionals

**Recommendation 2:** Build a composite understanding of each neurodiverse student's academic and social-emotional needs through multiple data sources

**Recommendation 3:** Establish 'Inclusive Practice' as a Whole-School Priority: school-wide implementation of an inclusive approach to curriculum and pedagogy such as Universal Design for Learning.

**Recommendations** to enact parent participation principles:

**Recommendation 4:** Create welcoming and safe settings for parents to share parent knowledge and expertise. Teacher education in parent engagement

**Recommendation 5:** Establish consultative groups from parents of neurodiverse students e.g. LEAPs

**Recommendation 6:** Schools support parents to support their child by serving as information hubs and, potentially, centres of integrated care. Seminars of lived experience as a way for parents to support parents.

*Figure 7.2* Barriers to participation – Principles and recommendations

### 7.6.1. Removing barriers to participation for neurodiverse students

The study established a number of barriers to participation for neurodiverse students that negatively affected their wellbeing:

- Academic or behavioural expectations that failed to acknowledge the student's learning or social-emotional needs and that resulted in failure, punishment, or social isolation.
- Student perceptions of academic and social pressure

To remove these barriers to participation schools must create developmentally appropriate school learning and social environments (**Principle 1**). Schools must also ensure an equal focus on social, emotional, and academic competencies (**Principle 2**).

To enact Principle 1 schools must rely on multiple sources of information. The general implications of Neurodevelopmental Disorders can be addressed, at the school level, through professional education that brings teachers up to date with current knowledge and research.

However, taking a person first, disability second perspective means that schools are obliged – from the perspective of professional standards and an ethic of care – to understand the individual child's specific learning, social and emotional needs. The example of Rory and Forbes (Chapter 6.6) illustrates that a diagnosis is a general descriptor that tells the teacher nothing of the child's personal learning journey or social-emotional needs.

#### Recommendation 1:

- It is recommended that schools create developmentally appropriate learning and social environments through complex data sets.
- It is further recommended that schools support teachers to include neurodiverse students through professional education and adequate in-class support.

Data on how well students are doing academically is a deciding factor in school quality, and examination success equates to educational success. Not only does this place enormous pressure on neurodiverse students, but NAPLAN and assessment data provide educators with no understanding of a student's social-emotional wellbeing. To enact Principle 2 schools must understand the impact of anxiety on students and understand what it means to have Dyslexia or ASD or ADHD. To achieve this, educators must first 'know students and how they learn' (AITSL, 2017)

## Recommendation 2:

- It is recommended that schools build a composite understanding of each neurodiverse student's academic and social-emotional needs through multiple data sources.

While Recommendations 1 and 2 focus on knowing the individual student, building a whole-school culture of inclusion is equally important.

## Recommendation 3:

- It is recommended that schools establish 'inclusive practice' as a whole-school priority and implement one of the many existing frameworks and approaches to inclusion that are familiar and proven in Queensland schools.

One example, the Universal Design for Learning framework (UDL) (CAST, 2019) is a whole-school, whole-class approach. It does not single out students for intervention or draw attention to their difficulties by requiring them to leave the classroom for learning support. Neurodiverse students are able to experience academic and social belonging and connectedness in all classrooms.

These recommendations have ramifications beyond schools, with implications for systems change. If high school educators are to receive adequate support to include neurodiverse students in their classes, consideration should be given to increasing the numbers of qualified Learning Support teachers, educational psychologists and Guidance Officers in Queensland schools. If the issues of social justice that affect the inclusion of neurodiverse students in Queensland schools are to be addressed, consideration should be given to reviewing the current system of verification in Queensland schools for its capacity to promote 'equity and excellence' for all Australian students (MCEETYA, 2008, p. 6).

### 7.6.2. Removing barriers to participation for parents of neurodiverse students

The study established a number of barriers to participation for parents of neurodiverse students:

- Misconceptions around parent involvement and engagement

Dismantling these misunderstandings requires schools to create welcoming settings that encourage parents to share how they support their child's learning and schooling journeys (**Principle 3**). This involves an open and attentive attitude to parents' reasons for being engaged and involved (**Principle 5**).

- Access to services and authoritative information

Schools are in a position to empower and support parents with authoritative advice and access to coordinated services (**Principle 4**).

- Confusion over appropriate levels of parent involvement

The study suggested a need for clearly articulated and consistent guidelines for parent invovlement at school that respond to child and family needs (**Principle 6**).

- Negative attitudes towards parent expertise

The study suggested that parents are the experts in their child's social-emotional needs so must be involved in, and informed of, the decision-making processes relating to their child's inclusion (**Principle 7**).

The following recommendations suggest how these principles might be enacted in practice, with the aim of creating a parent-school mesosystem that recognises the wellbeing of neurodiverse children as a shared responsibility between school and family, and that responds to the support needs of these students and their parents.

To enact Principles 3, 5 and 7, and to develop broader cultures of inclusion that extend to the parent community, schools must attend to the needs of individual families through a commitment to dialogue over one-way communication, and an open attitude towards parent expertise.

## Recommendation 4:

- It is recommended that schools create welcoming and safe settings for parents to share their parent knowledge and expertise.

- It is further recommended that high school educators are provided with ongoing teacher education about engaging with parents.

To enact Principle 6, schools might accommodate parent perspective through consultative groups drawn from among the parents of neurodiverse children within the school community.

Lived Experience Advisory Panels (LEAPs) present as an example of community consultative groups and are well-established in the sectors of disability services, health and mental health. LEAPs provide advice on current and emerging issues from a lived experience perspective, and, importantly, help bridge the gap between stakeholder and professional perspectives, and between experiential and theoretical knowledge (Byrne, Happell, Welch & Moxham, 2012). These were key issues raised in the current study.

In recent years, the lived experience of parents of SEN students has influenced the inclusion and support initiatives of education authorities (Deloitte, 2017). However, truly inclusive education responds to individual and local need, and this necessitates ongoing parent perspective and feedback as issues arise.

## Recommendation 5:

- It is recommended that schools establish consultative groups, such as LEAPs, from the parents of neurodiverse students to provide parent perspectives on home-school communication strategies and parent participation.

To enact Principle 4, schools are in a position to coordinate information workshops with visiting professionals from Queensland Health and support groups such as SPELD.

### Recommendation 6:

- It is recommended that schools support parents to support their child by serving as information hubs.

This recommendation has ramifications beyond schools, with implications for systems change. If schools can help to empower and support parents with authoritative advice and access to coordinated services, consideration should be given to the potential role of schools as centres of integrated care.

There are further implications for parents, and for the researcher. For the most part, the participants shouldered the burden of supporting their neurodiverse child with minimal advice or assistance from schools and other agencies. They commented on their sense of loneliness, as a parent at high school compared with primary school. Sharing their stories and reflecting on their lived experience is a way relieving the isolation of this parenting role and the stigma and misconceptions around the intensive role these parents play in their children’s lives. Consideration should be given to establishing seminars of lived experience for parents of neurodiverse children, who have first-hand knowledge of issues such as negotiating education, medical, mental health and allied health systems, as well as experience of living with a neurodiverse child.

Consideration should also be given to the role of facilitator – someone is needed to coordinate and manage seminars of lived experience and the participants suggested the researcher take on this role as a follow-on to the study.

## 7.7. Suggestions for further research

One of the central themes in Bronfenbrenner’s work is the ‘impossibility of understanding individual development in isolation’ (Darling, 2007, p. 2005). As a phenomenological study, this research has shed some light on the microsystems of home and school, and the mesosystems of home-school interactions for a small group of parents of neurodiverse children. To combat the type of negative or even indifferent attitudes described by the study participants, and to better understand the developmental trajectories of neurodiverse children, there is a need for further research. The impact of school environments on neurodiverse children needs to be explored further, in different contexts and with larger study populations. Similarly, the ways in which parents of neurodiverse children attempt to alter home and school environments also should be investigated on a larger scale. This is necessary for the wellbeing of neurodiverse children and to enable schools to develop more satisfactory partnerships with their parents. Other avenues for future research include:

### 7.7.1. Future research: Community psychology

Beyond EST, Community Psychology presents as an alternative and potentially valuable way to investigate the areas of adolescent wellbeing and family-school partnerships. Its strengths lie in an ecological focus on broader health issues that acknowledges social inequality as an aspect of health dynamics.

- It is recommended that the concepts of adolescent wellbeing and family-school partnerships are explored from the perspective of Community Psychology.

### 7.7.2. Future research: Belonging and connectedness

In the current study, parents provided insights into the external indicators of their neurodiverse child's anxiety but explained that their young adolescent was often unable to properly articulate how they felt. Asking older adolescents or young adults to describe their schooling experiences would illuminate this critical issue.

- It is recommended that the concepts of belonging and connectedness are explored from the perspective of older neurodiverse adolescents.

### 7.7.3. Future research: The work of school and home

The current study addressed the issue of adolescent wellbeing from the perspective of parents of neurodiverse children and focussed on academic and social inclusion.

- It is recommended that future research investigate parent and teacher perspectives on what constitutes the 'work of the school' and the 'work of home' in supporting the dimensions of wellbeing.

### 7.7.4. Future research: Helicopter mothers

In the current study, the participants expressed ambivalent attitudes to the label ‘helicopter mother’.

- It is recommended that future research investigate this phenomenon using a different methodology that allowed for a larger and more diverse participant sample.

### 7.7.5. Future research: Authoritative information

While there is a plethora of online advice for parents about mental health issues and Neurodevelopmental Disorders, the participants in the current study did not appear to value this information to the same degree as professional or word-of-mouth advice.

- It is recommended that future research explores the uptake of online information and advice by parents of neurodiverse children, and how to best target this demographic.

### 7.7.6. Future research: Lived Experience Advisory Panels

While there is great potential for establishing Lived Experience Advisory Panels made up of parents of neurodiverse children, LEAPs are more commonly used in the areas of mental health and disability.

- It is recommended that future research explores the possibilities of parent LEAPs in schools, and seminars and workshops for parents of neurodiverse students.

## 7.8. Final comments

In chapter 1, I commented on the assumptions around inclusion, anxiety and parent-teacher relationships that I held as a high-school teacher. These were altered by further education and by my parenting experiences, especially as the parent of a child with learning difficulties and anxiety. However, conducting this study has provided significant insights into some remnant attitudes. These realisations were not always pleasant, and I discovered that I held hierarchical attitudes towards disability and inclusion, and judgemental attitudes towards other parents. I discovered that I had placed my own child's difficulties on a scale of comparison that ranked him between "thankfully not as bad as him" and "I wish he was as confident as her". And even though I had lived in small, rural communities, I also discovered that I had been unjustifiably complacent about my son's access to authoritative advice and effective interventions. If an experienced educator and parent of a child who has struggled can be this judgemental, this appraising and this complacent; and if it takes this kind of research journey to adjust those attitudes, then it is likely that negative attitudes to neurodiverse students and their parents strongly persist in school communities.

Another result of this research journey has been the shift in my attitudes towards the participants. I began by seeing them as informers and ended up seeing them as collaborators in my research. This discussion would not exist without their generous determination to share their stories so that other families might benefit, and so that other neurodiverse young people might thrive, not just survive, at school. A logical development of this research, therefore, will be to help the participants share their stories of lived experience, not just with academics and educators, but with other parents of neurodiverse students. As Mary put it, these parents need to know they are not alone and that 'there are others in the same boat'.

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# IMAGES

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*Books* (Figure 1.2)
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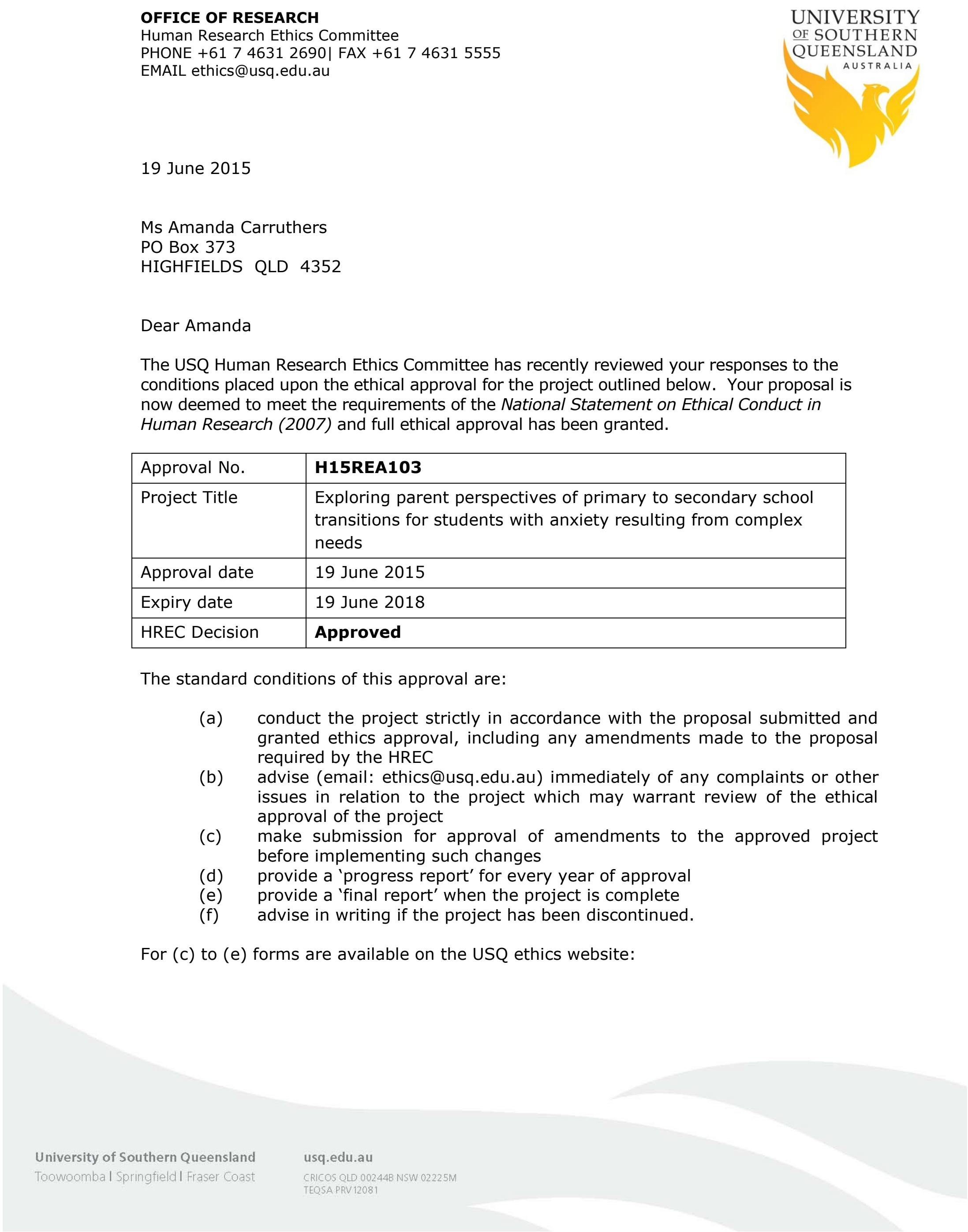
# APPENDICES

# Appendix A: Table 1

| Emergent themes on adolescent wellbeing from research | Emergent themes in disabilities in adolescence literature | Perspective of students with disabilities – "the good life" | What promotes a sense of belongingness at school for students with disabilities? | Literature review of student engagement for students with mental health needs | Perspective of students with ASD | Perspective of students with ADHD | Perspective of students with SLDs |
|---|---|---|---|---|---|---|---|
| Education Services Australia, (2018) | Maxey & Beckert (2016) | Foley, Blackmore et al., (2012) | Robinson & Truscott (2104) | Holdsworth & Blanchard (2006) | Goodall (2012)<br>Bauminger & Shulman (2003)<br>Sproston, Sedgewick & Crane (2017) | Wiener & Daniels (2016)<br>Michail (2011) | Leitão et al., (2017) Claassens & Lessing (2015) Livingston, et al., (2018). |
| Technology and wellbeing | Family relationships | Friends | Friends | Relationships with teachers and with peers | Friendships | Friendships | Friends<br>Peers & relationships |
| Social and school connectedness | Friends and peers | Family | Peer acceptance | Informed teachers | Peer acceptance, peer rejection and bullying | Peer relationships | Whole school supportive environment |
| Relationships and respect | School, technology, and extracurricular activities | Anxiety relating to performance at school | Feeling valued | Continued learning | Learning environment – sensory issues & class sizes | Learning environment - sitting still, being quiet &concentrating | Learning environment – curriculum content & pace of instruction |
| Help-seeking and schools | Bullying | Coping strategies/resilience | Feeling capable | Avoiding stigma | Belonging and connectedness | Social environment to support behaviour | Belonging – failure & self-esteem |
| School climate | Psychosocial development issues | Personal growth and development | Supportive relationships with key adults at school | Strong decision-making and control | Need for safe places within the school environment | Academic & organisational scaffolding | knowledge of learning issues, differentiated teaching |
| Tiered-approach to support | | | | | Supportive relationships with teachers | Supportive relationships with teachers | Teacher attitudes to diagnosis |
| Best practice teaching methodologies | | | | | Supportive school environment | Positive whole school behaviour | Emotional support/ coping strategies |

# Appendix B: Ethics approval letter



**OFFICE OF RESEARCH**
Human Research Ethics Committee
PHONE +61 7 4631 2690| FAX +61 7 4631 5555
EMAIL ethics@usq.edu.au

19 June 2015

Ms Amanda Carruthers
PO Box 373
HIGHFIELDS QLD 4352

Dear Amanda

The USQ Human Research Ethics Committee has recently reviewed your responses to the conditions placed upon the ethical approval for the project outlined below. Your proposal is now deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research (2007)* and full ethical approval has been granted.

| | |
|---|---|
| Approval No. | **H15REA103** |
| Project Title | Exploring parent perspectives of primary to secondary school transitions for students with anxiety resulting from complex needs |
| Approval date | 19 June 2015 |
| Expiry date | 19 June 2018 |
| HREC Decision | **Approved** |

The standard conditions of this approval are:

(a) conduct the project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments made to the proposal required by the HREC
(b) advise (email: ethics@usq.edu.au) immediately of any complaints or other issues in relation to the project which may warrant review of the ethical approval of the project
(c) make submission for approval of amendments to the approved project before implementing such changes
(d) provide a 'progress report' for every year of approval
(e) provide a 'final report' when the project is complete
(f) advise in writing if the project has been discontinued.

For (c) to (e) forms are available on the USQ ethics website:

University of Southern Queensland
Toowoomba | Springfield | Fraser Coast
usq.edu.au
CRICOS QLD 00244B NSW 02225M
TEQSA PRV12081

http://www.usq.edu.au/research/ethicsbio/human

Please note that failure to comply with the conditions of approval and the *National Statement (2007)* may result in withdrawal of approval for the project.

You may now commence your project. I wish you all the best for the conduct of the project.

AJackson

**Annmaree Jackson**
Ethics Coordinator

Copies to: Amanda.carruthers@bigpond.com.au

# Appendix C: Invitation to participate

Amanda Carruthers

June 10 2015

Exploring parent perspectives of primary to secondary school transitions for students with anxiety resulting from complex needs.

## Invitation to Participate

Dear Parent,

I would like to invite you to participate in either a focus group or individual interview to talk about your child's transition from Primary to High school. 2015 is an important year as both Year 6 and Year 7 move up to high school. This can be a challenging time for all students and parents, but particularly for students who experience anxiety as a result of learning, social-emotional or behavioural needs.

You are being invited because you have a child who has experienced anxiety and who has experienced learning, social-emotional or behavioural difficulties at times.

This invitation has been forwarded to you by your child's Primary school principal or Learning Support teacher. This is an invitation to participate only and you are under no obligation to proceed further with this invitation.

## What is the purpose of the research study?

This research is for the purposes of my Doctoral Study. I am a PhD candidate at the University of Southern Queensland and I am interested in inclusion and belonging within school communities. I am a parent of a child with anxiety and learning needs and I taught with Education Queensland for nearly 20 years. My research aims to understand transitions, and the impact on students and families, from the parents' perspective.

I have included further details of the research study in the **Participant Information Sheets.**

## What does a focus group involve?

A focus group is a chance for people to answer questions in a group setting.
There will be about five or six other people in the room during the focus group, and all will be parents whose child has experienced anxiety as a result of learning, social-emotional or behavioural needs and who has moved up to high school in 2015.

The focus groups will take approximately two hours at a location and date to be determined but which will be convenient to parents.

In the group, we will talk about your experiences as a parent and how you have helped to support your child through this transition.

### Individual Interviews

Following the focus group discussion you may wish to discuss your experiences further in an individual interview.

Alternatively, you may not feel that a group discussion is right for you and might prefer to meet privately to discuss your experiences. I have included further details of the Individual Interviews in the **Participant Information Sheet - Interviews.** Interviews will take place at a location and date to be determined but which will be convenient to you.

### The Next Step

My contact details are included in the Information Sheets. I have not been provided with parent contact details and it is up to you whether you proceed to contact me.

Thank you for considering taking part in this research.

Yours Sincerely,

Amanda Carruthers

# Appendix D: Participant information letter

**University of Southern Queensland**

## Participant Information for USQ Research Project Interview

### Title of Project

Understanding the lived experiences of parents with children having complex needs who are transitioning between primary and secondary school contexts

**Human Research Ethics Approval Number:** H15REA103

### Research Team Contact Details

| **Principal Investigator Details** | **Supervisor Details** |
|---|---|
| Ms Amanda Carruthers | Dr Lindy Abawi |
| Email: Amanda.carruthers@usq.edu.au | Email: lindy-anne.abawi@usq.edu.au |
| Telephone: (07) 4631 5440 | Telephone: (07) 4631 1168 |
| Mobile: 0458785054 | Mobile: 0418747270 |

### Description

This project is being undertaken as part of a Doctor of Philosophy. The purpose of this project is to examine the experiences of parents and carers of children who:

a. Experience anxiety as a result of learning, social or behavioural needs
b. Have been identified as needing additional support during primary school
c. Are transitioning between mainstream primary and high school.

I request your assistance because the transition between primary and secondary school is an important time in the lives and education of young people and, in turn their parents. For students with complex learning, social or behavioural needs, transition can be especially stressful as students do not always have the academic, social or emotional skills to help them adjust to new social and learning environments.

From personal experience, I know that parents know their child's needs but may experiencing difficulty voicing their concerns in this new school environment. Who should they talk to? Where should they go? This study aims to discover the kinds of support from, and partnerships with, schools that parents value when helping their anxious child transition from primary to secondary school.

### Participation

Your participation will involve participation in an interview that will take approximately an hour of your time. The interview will take place at time and place convenient to you. Questions will be open ended e.g.

When did you first become aware that your child had levels of anxiety?
What supports were provided form your child in Primary School?
What supports were provided in preparation for the transition to secondary school?
In what ways has their high school provided for your child's needs during transition?
In what ways have you been involved in the transition process?

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.  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 may not directly benefit you unless you have other children progressing through the school system. However, it has the potential to benefit others in similar circumstances in the future by informing effective transition programs and the building of stronger partnerships between schools and families. Thus, resulting in better educational outcomes for children with complex learning, social or behavioural needs and therefore better outcomes for families and schools.

## Risks

There are minimal risks associated with your participation in this project though reliving difficult episodes of your child's school experiences may bring back bad memories. Sometimes thinking about the sorts of issues raised in the interview can create some uncomfortable or distressing feelings.  If you need to talk to someone about this immediately please contact 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 as required by law and internal requirements. You will have the opportunity to verify your comments and responses prior to final inclusion. Transcripts of the recordings will be retained for 5 years and then destroyed. I will be the only person with access to the recordings because I will be transcribing the recording myself. 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: Participant consent form

University of Southern Queensland

## Consent Form for USQ Research Project Interview

**Project Details**

**Title of Project:** Understanding the lived experiences of parents with children having complex needs who are transitioning between primary and secondary schools

Human Research Ethics Approval Number: **H15REA103**

**Research Team Contact Details**

**Principal Investigator Details**
Ms Amanda Carruthers
Email: Amanda.carruthers@usq.edu.au
Telephone: (07) 4631 5440
Mobile: 0458785054

**Supervisor Details**
Dr Lindy Abawi
Email: Lindy.abawi@usq.edu.au
Telephone: (07) 4631 11680
Mobile:

**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 I will be provided with a copy of the transcript of the interview for my perusal and endorsement prior to inclusion of this data in the project.
- 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.
- Agree to participate in the project.

Participant Name

Participant Signature

Date

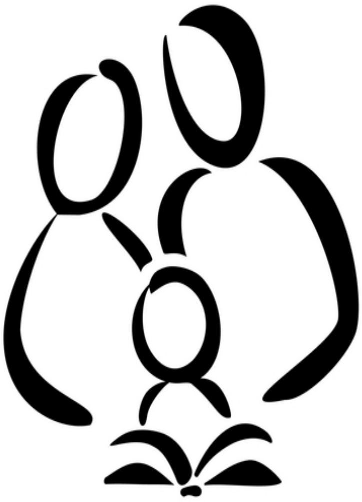
**Please return this sheet to the Researcher prior to undertaking the interview.**

Page **1** of **1**

## Appendix F: Flyer – invitation to parents

# INVITATION TO PARENTS

Transitions can be challenging – for **students with anxiety** and for their parents who are supporting them through this time.



UNIVERSITY OF SOUTHERN QUEENSLAND

**AMANDA CARRUTHERS**
University of Southern Queensland
46315440 |0458785054

Amanda.carruthers@usq.edu.au

**Does your child experience anxiety related to Learning Difficulties; Behavioural Difficulties or Social-Emotional Difficulties?**

**Did your child begin high school in 2015?**

I am inviting parents to participate in a research study that examines parent perspectives of the transition from primary to secondary school.

I am a PhD candidate at the University of Southern Queensland and also the parent of a child with anxiety and learning needs.

My research aims to understand anxiety during transitions, and the impact on students and families; from the parents' perspective.

If you are interested in sharing your experiences in a one-to-one interview (in person or phone interview) please contact me for more details.

# Appendix G: Request for amendment to an approved human research ethics project

## Appendix H: Interview schedule draft

# INTERVIEW SCHEDULE – DRAFT

## Primary School

I would like you tell me about (child's name), and how they got along in primary school:

- What did they enjoy most about primary school?
- What did they find most challenging?
- How did the teachers at (Primary School name) help them manage these challenges?
- What specific support has (child's name) received in primary school?
- Does your child need any specific resources or equipment? Were these available in their primary school?
- Did (child's name) have a friendship group at primary school?
- Did these friends move up to the same high school as (child's name)?
- Do you feel that (child's name) was ready to move up to high school?
- While (child's name) was still in Year 6, what aspects of transitioning were you most concerned about?
- Did (child's name)'s Year 6 teacher share your concerns?
- What did your child's teacher/s feel would be their biggest challenge in moving up to high school?

## Choosing a High School

Could you tell me how you chose your child's high school?

- Is it your nearest high school?
- Did you consider other factors such as support staff or facilities? Pastoral Care Programs? Facilities such as sports or arts programs/ resources? School leadership/Principal?

How did you hear about the different high schools in your area?

- Other parents?
- Your child's Primary school teachers?
- The Primary school Principal or Guidance Officer?
- Other?

Have you needed to make any adjustments in order for your child to attend this school?
For example, travel/ change work arrangements/ other?

## Preparing for Transition

Could you tell me how (child's name) was prepared for the transition to Year 7?

- Did the Year 6 students visit any of the local high schools?
- Did the high school offer any open days to either parents or Year 6 students?

- Did any high school staff visit (child's name)'s school?
- Did (child's name) attend an enrolment interview for their new high school in Term 4, Year 6?
- Were there parent information events at any of the high schools you looked at?
- Did you have the opportunity to attend any parent workshops dealing with issues such as subjects in high school; adolescence; technology; other?

Did child's name receive any individual preparation for transition that would help him/her adjust to his/her particular challenges?

- Did they have a personalised visit to the high school?
- Did they receive specific information that would help them adjust to the new school eg meetings with the high school Guidance Officer or Year Coordinator?

To your knowledge, did (child's name)'s primary school provide the high school with specific information about their needs? (That could be about Learning, Social, Behavioural or Emotional needs)

Do you think that the Primary and High school coordinated the transition well?

## Junior Secondary:

I would like to ask you about (child's name)'s experience of high school so far.

## Teaching Staff:

Could you tell me about (child's name)'s teachers?

- Do (child's name) teachers just teach Years 7 -9 or do they work in all year levels?
- What is (child's name)'s favourite subject so far?
- Why do you think that is?
- Does (name) seem comfortable in his/her classes?
- What steps have (name)'s teachers made to get to know (child's name)?
- How have they helped (child's name) settle into their new class?
- Does your child have a homeroom teacher? A mentor? A house teacher?
- The Department of Education has made a commitment to employing "teachers experienced with teaching young adolescents". To your knowledge, are (child's name) experienced Middle Years teachers?
- In your opinion, do the teachers at your child's high school have experience in (child's name)'s learning /social /behavioural issues?
- Do you feel that they are well equipped to look after (child's name)'s needs?

## Support:

Could you tell me what support has been made available to your child so far, in their high school?

How is this different to what happened in primary school?
- How did you know what support (child's name) was receiving in primary school?
- Did you ever meet support staff there?

Are you aware of specific staff members (such as teacher aides, Learning Support teachers, Guidance Officer?) who may be supporting (child's name)?
- Have they contacted you to introduce themselves or to discuss (child's name)'s needs / support program?

In primary school, did (child's name) ever visit other support professionals such as Occupational or Physiotherapists or Speech Pathologists?
- Was this a school-based service or was (child's name) a private patient?
- In high school, has (child's name) continued to see (Occupational/Physio/Speech)?
- Did the school coordinate this or is (name) a private patient?
- If school-coordinated, how have you been made aware of this support?

Has your child received specific advice / support in:
- time management (eg using a diary, planning assessment)?
- navigating the school (eg individualised maps or timetables)?
- adjusting to new social groups (eg encouraged to join an interest club)?

## Resources:

What resources are available to (child's name) to help support their needs?
- Do you feel that these are adequate?
- Have you been involved in any discussions with the high school about resources?

## Student Wellbeing:

We have discussed how, at primary school, anxiety was an issue for your child.

- Have you had an opportunity to discuss this with anyone at your child's high school?
- Have any of your child's teachers contacted you about your child's anxiety?
- Were specific programs put in place to help your child cope with the new environment (eg access to quiet areas where they can spend time if upset or needing to be away from other students)?

What about at lunch and break times?

- Where does your child normally spend these?
- How do you know (ie has your child / a teacher told you)?

What do you about the school's pastoral care program?

- Is there a specific teacher or staff member who looks after your child's social-

emotional welfare?
- Who do you contact when you have concerns about your child's well-being?
- Have you had any incidents yet where your child may have been upset by something that happened at school?
- Were you contacted by the school? Did you make contact yourself?

How does (child's name)'s high school encourage students to feel a sense of belonging?

Do you feel that they encourage parents to feel a sense of belonging also?

## Parent and community involvement / Communication:

How does your child's high school communicate with parents?

- Do they have a newsletter?
- Does the school run parent workshops or information evenings?
- How are you kept informed about what your child is doing in their school day?
- Do individual teachers email you?
- Is there a specific person with whom you can touch base to find out how your child is going?
- Who contacts you if things are not going well?
- How is this done?

In what ways have you been invited to become involved in the school?

- Are parents welcome at school assemblies?
- Do volunteers help at tuckshop or in other areas of the school?
- Do parents help with learning support at all or perhaps with clubs or sports training?
- How have you found out about these ways to get involved?
- How have you found out about events such as assemblies or awards?

## Appendix I: Research journal excerpts

**Journal extract October 13th, 2015**

Difficulties in gaining parent trust – key themes

- no responses from flyers in school newsletters or from psychologist's rooms
- one parent responded to invitation from schools but as a parent I have known for some time I was reluctant to take her up
- a few parents became "door keepers" – telling other parents and arranging meetings and introductions. Like a pyramid
- wariness of parents – the numbers of meetings, the "courting" process and eventual approval
- these parents have gone through years of having to convince schools and medical professionals that there was "something wrong" with their child other than poor parenting, low intelligence/ability etc
- how this makes me feel – explain my own position and all I have done with J. and how I have tried so many avenues.

**Journal extract November 2, 2015**

Difficulties in finding participants

M. has organised a coffee with F. (Parent C) so that I can meet her with a view to a possible interview. This has been such an operation taking a long time (maybe 7 or 8 weeks?). M. has mentioned me and J. a few times – kids in similar situations etc, then she mentioned my research and then that I needed participants – all on separate occasions. I have met F. before but as M's friend, not as parent or researcher. So, we have a 10.30 coffee date – M., F. and I – and F. has said in advance that she can't stay and only has 30 minutes. I ended up getting home around 1.30! The first part of the "meeting" was about fussing around the coffee (M. was nervous) and then we got to talking about schools and boys and I heard F.'s story about her son's difficulties, about the "specialist merry go round", about finding the right school etc. In short, all the things which we've gone through. And I think it was the fact that we had done all this and been to the same organisations (SPELD, developmental optometrists, paediatricians, educational psychologists etc) that made F. decide that I was ok. In the end, M. took a complete back seat and only joined the conversation occasionally, as M's son & F.'s older son both have similar difficulties and issues.

**Journal extract November 7, 2015**

Finding participants through chain referral

Heard from E. (Parent D) – she has found three other parents for me already and is organising a time for me to meet them. None of them know each other so three separate meetings. It has just occurred to me that this is how I will find my participants, through word of mouth. The wording of the invitation sent by schools was too formal and accusatory and I'm not sure that I would want to confide in a stranger. There is a lot of criticism from other parents (and members of the public) who don't understand the reasons your child is having a melt down and put it down to poor parenting.

**Journal extract November 12, 2015**

Difficulties in finding participants

Met three parents for coffee yesterday and one was openly hostile until we got talking and then she was much warmer (and agreed to be interviewed). This is so interesting in terms of qualitative research. I don't think some would talk to me if we didn't have some common ground. And the parent who was hostile has clearly had so many negative experiences with schools – she has four children who have differing need and levels of anxiety so a lot of negotiating with schools.

**Journal extract November 18, 2015**

Parent disclosure concerns

Interview with T. (Parent B) at a local cafe. Choice of venue concerned me because of lack of privacy but didn't worry T. I was introduced to her by M. (Parent A) and knew her from school but none of the children were in the same grade so didn't know her situation. It has taken four casual conversations (not recorded) for her to admit her child has anxiety – she was adamant that this wasn't the case but maybe sees some stigma about anxiety. "Admit" is perhaps not the right word. Having interviewed her now, I hadn't realised that she had several children with learning, social /emotional issues and one with behavioural issues so I'm not sure we were on the same page at first. We ended up talking about her eldest child more than her Year 8 student. The older son has a school learning support plan and has completed several psychologist programs – CBT etc for anxiety. The main theme that emerged here is that transition issues do not necessarily resolve themselves in the first year of high school. This student is completing Year 10 and it has taken this long to find the right support for his needs (at the same school). This is why I need to widen the time frame from transition and Year 7/8.

**Journal extract June 9th, 2017**

Conceptual Metaphor – Lakoff & Johnson (1980) ‘we think metaphorically’ (Metaphors we live by). The conceptual system – how we think and act – is metaphorical and structures what we perceive, how we get around in the world, how we relate to people. Concept is metaphorical and concept structures everyday activity – conceptual metaphor eg ARGUMENT IS WAR. Metaphorical entailments/ systematicity

The parents wanted to discuss their ‘journey’ as a whole. They tell a linear story but stop to elaborate on significant events – these are interruptions to the journey that indicated that all was not well. They talk of ‘navigating the school system’, they talk about the ‘road they have travelled’ with their child. All their efforts are directed towards ‘equipping’ their child for a different journey their child. So broader metaphor for longer experience of school – journey of schooling – something that moves forward but with common way points (year levels), hazards (academic failure, bullying) and has a clear finishing point.

Societal/ cultural norms of child rearing/ parental role can be seen as a compass, but this cannot always guide the path students with disability must take. Parents need a new road map. Parenting a child with needs is a different experience from their other parenting experiences. There is a sense of ‘navigating’ the school system ‘blindfolded’ – feeling their way. Their existing ‘road map’ (from previous experience) did not apply to this ‘new terrain’.

The parents use metaphor to explain why their parenting experiences (of advocacy and supervision, pathfinding and support) are at odds with cultural norms / social expectations around adolescent independence. They talk of their ‘disconnect’ from other parents because they have taken a different path or had a different parenting journey.

Would diagrammatic representation/ visual metaphor work here? ie map outlining identified themes / map out experiences. Metaphor helps bridge the gap between your experiences and my experience when words are inadequate.

## Appendix J: Unabridged transcript Eileen

**Researcher:** So thankyou E. for agreeing to do this. Could you tell me about your daughter E.? Tell me about her learning issues.

**Eileen:** Um, yeah, E. was, it was probably not until we got to pre-school that E.'s problems started to evolve. She was always, like having lots of siblings, very engaged with everyone, very social. She was the baby in the street; I don't think she ever even had a bath that she didn't have an audience! It's like she always, she was always a crowd gatherer (laughs). The kids would, um, whatever was going on … if there was a fashion parade at school they'd somehow manage to have her as the little model (laughs) or if they were doing a speech exam she would be an exhibit! Like she was sort of, yeah, poor old E. had this interesting little life…

But then she got to pre-school and she was very…. And I didn't pick up this anxiety … which was silly (sighs) not knowing; but every day she'd say, "I don't want to go to Holy Innocents when I'm in Grade 7". She'd say that every morning and then she'd cry and she wouldn't want to go to pre-school and it just … And from a little one that went to Kindy happily, that was such a big change.

**Researcher:** So she'd gone to Kindy?

**Eileen:** She'd gone to Kindy, but … She'd gone to (name) and she'd been … she'd teamed up with a little girl on her first day and they were little friends, but this little one left after about six weeks and once she left E. was… she just seemed …. There was a very disabled little one in the Kindy and E. used to stay with the aide and him; she was very interested in what went on into his care. He was in a wheelchair and needed full time care and she used to, um, stay with the aide and um …. That's how she went through Kindy. She'd never sleep; she was sort of put up in the office at sleep time because she was, you know, she hadn't slept since she was one. She was just one of those kids that never settled. Um, you know, we got to (school name) and she just, it turned out what she hated was the obstacle course every morning; they used to do that first thing. And with all her spatial issues; and she hates playgrounds, she hates … you know, she's not good at team sports and she's not good at working out what's going on in the game …

**Researcher:** Did you notice that before Kindy?

**Eileen:** No, not at all.

**Researcher:** Because there hadn't been the opportunity?

Eileen: Yes, and like the kindy teacher would say things like. "Oh she's not good with scissors", um, but she was left-handed and, um, I'd say "well she doesn't use scissors at home". I didn't sort of click but looking back those things were probably more meaningful than, um, than they were to me then. I certainly didn't have any worries when she was little. Um, she seemed to go through pre-school socially quite fine, she, you know, I remember the end of the year report there was no obvious problems with the teachers then. It was just this, every day, this anxiety about definitely not being there in Grade 7; and what it turned out was, she'd seen the kids practising for sports day and they were doing high jump, so she knew that was ahead of her in Grade 7 and she wasn't … she was not going to be there when that happened! (laughs)

**Researcher:** So she wasn't worried about Grades 1 – 6?

**Eileen:** Well, she didn't realise that it started in about Grade 3! (laughs).

**Researcher & Eileen:** Both laugh

**Eileen:** She'd just seen those Grade 7's doing things she was never going to do and that set her off so, um, she got to Grade 1 and probably, it wasn't until the end of the year that the teacher said, "I've got real concerns about E."; she said … because all the other kids, you know families tend to get… you know, the other kids go through without any problems and then E. came along and they… she said, "Look I just thought she was being lazy and not trying". And she said "I sort of yell at her to try and get her going and" she said, "she'd just look at me with this fear in her eyes" … and, um, yeah, she just wasn't learning anything.

**Researcher:** And what about physically, was she …?

**Eileen:** Physically, um, I suppose Grade 1 well you can get away with a lot because they're all little and learning…

**Researcher:** and a bit uncoordinated?

**Eileen:** Yeah, and they're sort of trying to group them and work out what their levels are. But she used to, um, I think the very first day they had to write a little story on Monday, about their weekend and I think the teacher wrote on the board, you know, something… we can write something like "I went to the park" so every Monday morning that's all E. ever wrote for the whole year (laughs) You know, you don't go to the park that much! But, yeah, she'd just seen…

**Researcher:** That was the suggestion?

**Eileen:** That was it, that's what she ran with. But she wasn't reading and she wasn't, she couldn't do maths to save herself … she had no idea. I, um, when she came home the first time with her little maths problems, it was just 1 + 2 and I was trying to explain it to her and she just looked at me, bewildered, and said "Mum, I have no idea what you are talking about".

# Appendix K: Extended narrative Eileen

It was probably not until we got to pre-school that Emily's problems started to evolve. She was always, like having lots of siblings, very engaged with everyone, very social. She was the baby in the street; she was always a crowd gatherer. But then she got to pre-school and she was very…. And I didn't pick up this anxiety … which was silly not knowing; but every day she'd say, "I don't want to go to (primary school) when I'm in Grade 7". She'd say that every morning and then she'd cry, and she wouldn't want to go to pre-school and it just … And from a little one that went to Kindy happily, that was such a big change.

She'd gone to (Kindergarten) and she'd been … she'd teamed up with a little girl on her first day and they were little friends, but this little one left after about six weeks and once she left Emily was a little lost. There was a very disabled little one in the Kindy and Emily used to stay with the aide and him; she was very interested in what went on into his care. He was in a wheelchair and needed full time care and she used to, stay with the aide and… That's how she went through kindy. She'd never sleep; she was moved to the office at sleep time because she was disruptive. She hadn't slept in the day since she was one. She was just one of those kids that never settled. At primary school and she cried every morning. It turned out what she hated was the obstacle course every morning; they used to do that first thing. She has spatial issues; and consequently, hates playgrounds. She's not good at team sports and she's not good at working out what's going on in the game.

Her spatial issues were not obvious to me before Kindy, they were met. But the kindy teacher would say things like. "Oh, she's not good with scissors", but she was left-handed and, I'd say "well she doesn't use scissors at home". I didn't click but looking back those things were probably more meaningful than they were to me then. I certainly didn't have any worries when she was little. She seemed to go through pre-school socially quite fine, I remember the end of the year report there were no obvious problems with her keeping up then. It was just this, every day, this anxiety about definitely not being there in Grade 7; and what it turned out was, she'd seen the kids practising for sports day and they were doing high jump, so she knew that was ahead of her in Grade 7 and she was *not* going to be there when that happened!

Well, she didn’t realise that it started in about Grade 3! She’d just seen those Grade 7’s doing things she was never going to do and that set her off so, ..., she got to Grade 1 and probably, it wasn’t until the end of the year that the teacher said, “I’ve got real concerns about Emily”

## Appendix L: Abridged narrative Eileen

It was probably not until we got to pre-school that Emily's problems started to evolve. Having lots of siblings, she was always very engaged with everyone, very social and she went to Kindy happily.

Her spatial issues were not obvious to me, but the Kindy teacher would say things like, "She's not good with scissors". But she was left-handed and, I'd say "well she doesn't use scissors at home". I didn't click but looking back those things are probably more meaningful than they were to me then. I certainly didn't have any worries when she was little.

She seemed to go through pre-school socially quite fine, I remember, in the end of the year report there were no obvious problems with her keeping up then. She got to Grade 1, and all our other kids went through without any problems, but she just wasn't learning anything. She wasn't reading, and she couldn't do maths to save herself. It wasn't until the end of the year that the teacher said, "I've got real concerns about Emily. She's just not progressing like the other kids", but nothing was ever done or suggested.

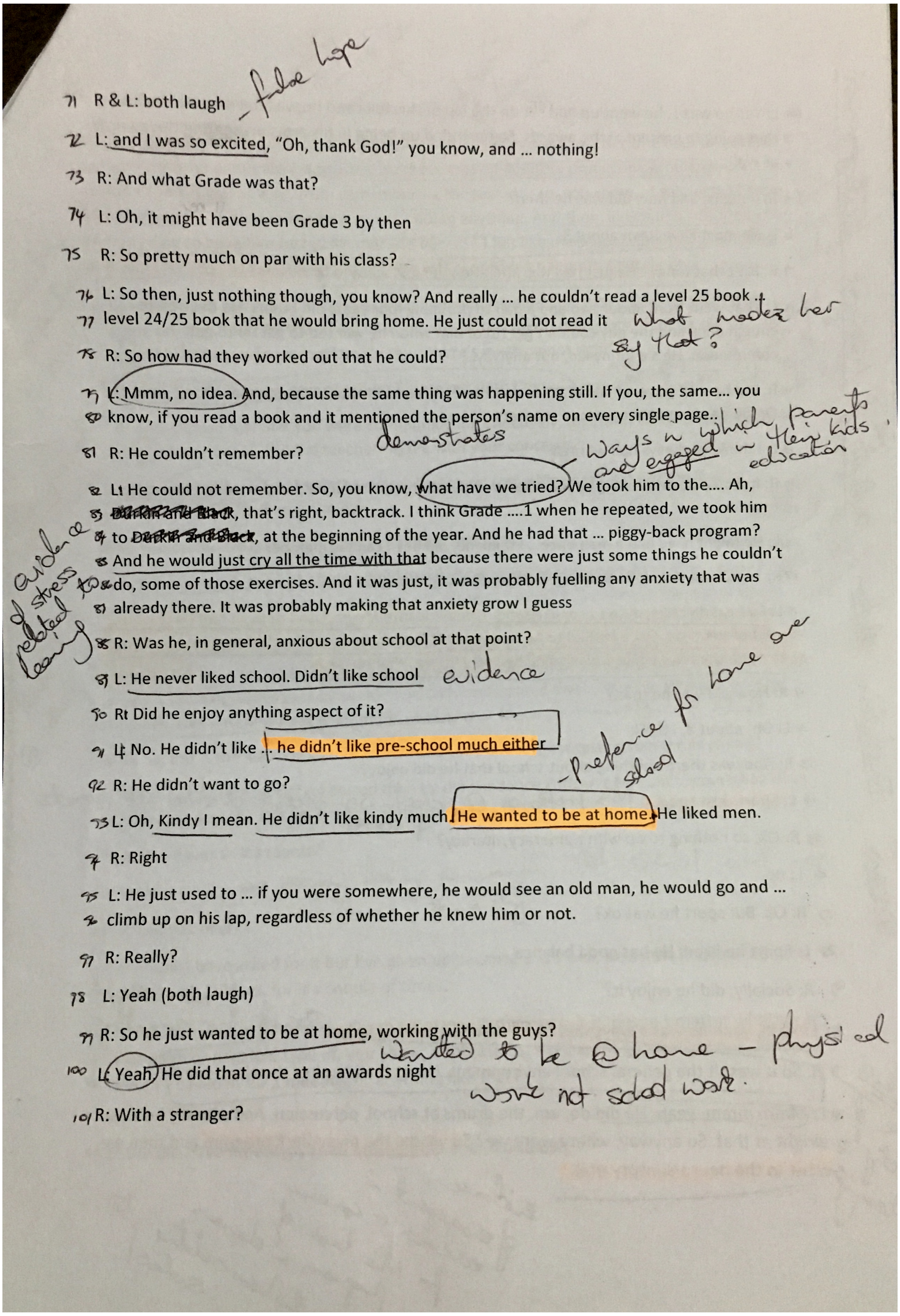
She got to Grade 2 and early in the year her teacher called me in and said, "Emily's obviously got some issues and I'd like a WISC test done on her". And then the psychologist said to me afterwards, "I have no idea how to decipher this, she has scored so low. But I know from spending time with she's not like that". Then, she went away, and nothing was ever done about it, so that was it.

At this stage, I had noticed very poor organisation. I helped her with everything. I used to go to school swimming with them, she could never get herself dressed and her togs on. The teachers were, "quick, quick, quick" and so I used to always help her, thinking she'll eventually get the idea, but she was very slow, couldn't tie her shoelaces; couldn't get her buttons done up.

And she cried every morning. It turned out she hated the obstacle course that they used to do first thing every morning. She has spatial issues; and hates playgrounds. She's not good at team sports and she's not good at working out what's going on in the game.

And she would not go to birthday parties because of the party games. She didn't know what was ahead, what was required of her. She'd often leave the invitation in the bag and not tell you. Or she'd cry and carry on about going.

# Appendix M: Example of initial notation phase



71 R & L: both laugh – false hope

72 L: and I was so excited, "Oh, thank God!" you know, and ... nothing!

73 R: And what Grade was that?

74 L: Oh, it might have been Grade 3 by then

75 R: So pretty much on par with his class?

76 L: So then, just nothing though, you know? And really ... he couldn't read a level 25 book ..
77 level 24/25 book that he would bring home. He just could not read it

What makes her say that?

78 R: So how had they worked out that he could?

79 L: Mmm, no idea. And, because the same thing was happening still. If you, the same... you
80 know, if you read a book and it mentioned the person's name on every single page..

demonstrates

Ways in which parents are engaged in their kids education

81 R: He couldn't remember?

82 L: He could not remember. So, you know, what have we tried? We took him to the.... Ah,
83 [redacted], that's right, backtrack. I think Grade ....1 when he repeated, we took him
84 to [redacted], at the beginning of the year. And he had that ... piggy-back program?
85 And he would just cry all the time with that because there were just some things he couldn't
86 do, some of those exercises. And it was just, it was probably fuelling any anxiety that was
87 already there. It was probably making that anxiety grow I guess

evidence of stress related to learning

88 R: Was he, in general, anxious about school at that point?

89 L: He never liked school. Didn't like school evidence

90 R: Did he enjoy anything aspect of it?

91 L: No. He didn't like .. he didn't like pre-school much either

– preference for home over school

92 R: He didn't want to go?

93 L: Oh, Kindy I mean. He didn't like kindy much. He wanted to be at home. He liked men.

94 R: Right

95 L: He just used to ... if you were somewhere, he would see an old man, he would go and ...
96 climb up on his lap, regardless of whether he knew him or not.

97 R: Really?

98 L: Yeah (both laugh)

99 R: So he just wanted to be at home, working with the guys?

Wanted to be @ home – physical work not school work.

100 L: Yeah. He did that once at an awards night

101 R: With a stranger?

# Appendix N: Table of thematic analysis – Mary

## Content Area: 1 Relationship with School

| Extract from transcript | Description close to the text | Interpretation of the underlying meaning | Sub-themes | Themes |
|---|---|---|---|---|
| *Quite often you get a call from the school and you go, "Oh no, what's it going to be this time?" So, it's quite unusual to have a positive phone call and have someone to give you good feedback* (2-4) | Mary explained how she was more used to receiving regular & negative phone calls – H's behaviours & social-emotional issues have made classroom interactions problematic.<br>This call from a teacher, relaying good news about Henry's class behaviour & learning stood out for Mary | Communication with the school is mostly negative – Mary feels quite negatively about her interactions with H's teachers. This was significant – Mary perceived it as a sign of progress & she felt positive towards this teacher for her acceptance of H & her efforts to understand Mary's needs for information | Schools tend to communicate the bad news more than the good news<br>Parents become wary of communicating with the school<br>Parents need to hear about the positives as well as the negatives | **Communication**<br>**Focus on student strengths**<br>**Effort to understand parent needs** |
| *I got an email and a contact and was asked if anything was happening at home that might cause this to happen and I'd had episodes of this at primary school. So, I said, "no, I didn't think anything was happening but it's probably because he can't get something right". And I was pretty much to the mark*. (34-37) | Mary was contacted by H's teacher to find out if anything at home might have precipitated an emotional outburst in class. Mary was able to explain why it might have happened – frustration with his abilities & perfectionism | Mary's knowledge of what triggered H's emotional outbursts enabled her to provide this rationale to his teacher. She also appreciated the teacher trying to understand what lay behind the outburst (rather than simply punishing the behaviour) | The need for teachers to understand why emotional outbursts occur<br>Opportunities to prevent future issue through home-school communication<br>Parent knowledge of child's emotional state | **Parent expertise**<br>**Metaphor:** *to the mark* – accuracy of parent knowledge<br>**Teacher knowledge of ASD**<br>**Social -emotional Issues/ ASD** |

| **Content Area: 1 Relationship with School** | | | | |
|---|---|---|---|---|
| **Extract from transcript** | **Description close to the text** | **Interpretation of the underlying meaning** | **Sub-themes** | **Themes** |
| *But quite often school doesn't let me know what's happened at school. I would say that school doesn't inform me as much as I inform school. (386-387)* | Mary had identified the importance of feedback about H's daily interactions at school. She stated that two-way communication between home & school does not happen regularly & that there is an imbalance in communication | Mary feels that<br>Parents of high school age children know little of what happens on a day-to-day basis.<br>P/T interviews provide the big picture but not the daily details | Home-school communication in high school<br>Limited bi-lateral communication<br>Parent's need to stay informed – to understand child's emotional state &/or academic progress | **Communication**<br>**Need for information**<br>**Monitoring** |

## Appendix O: Conceptual Metaphors. The story of conditional trust

| **Overarching theme** | **Subthemes** | **Key metaphors parents use to frame their experiences** |
|---|---|---|
| Parent involvement in school as a function of trust and as a means of ensuring their child's inclusion | Parent expectations of being included in the decision-making process for learning support – vigilant supervision | *Keeping a finger on it* (Eloise)<br>Getting in *teacher spaces* (Mary)<br>He still needs that *support behind him* (Eloise)<br>We could see that he needed *the support* (Eloise)<br>He needed a bit of *back-up to get him through* (Eloise)<br>It just needed that little bit of *a stepping stone* (Eloise)<br>Should I be more *on top of this?* (Eloise)<br>That's when I *came further* (Eloise)<br>I need you to be *on top of this* (Eloise)<br>I was still *keeping an eye on things,* but I was confident (Eloise)<br>So they couldn't *pull any language out* that I wasn't understanding (Frances) |
|  | Respect for parent knowledge | [It made me feel] very *out of control* of the whole situation (Eloise)<br>Complete *lack of control* (Eloise).<br>The teachers use *'teacher speak'* and I found it difficult to *put my arguments for Forbes forward* (Frances) |
|  | Communication | I'm really *pushing* for email communication (Mary)<br>*Parent loop* (Mary)<br>*Feedback loop* (Mary)<br>I just want to find that *middle tone* (Mary)<br>They seem to just *fall in a big void* (Mary)<br>*Touching base* (Mary)<br>*Time consuming* (Mary)<br>I'm trying *to push towards finding out a template* (Mary)<br>*A structure that could … break down some of the culture* (Mary) |

| **Overarching theme** | **Subthemes** | **Key metaphors parents use to frame their experiences** |
|---|---|---|
| | The battle to be believed | *Falling on deaf ears* (Frances) |
| | Advocacy actions | *I push in the IEP* (Mary)<br>Someone needs to be *taking a stand*<br>*I need to step in* (Mary)<br>I think you need to be *a helicopter parent* (Mary)<br>I had to *take her out (Michelle)*<br>I had to *stand up for her (Michelle)*<br>We decided then to *pull him out* (Frances) |
| | Reluctant advocates | Always *up at the school* (Eileen)<br>That *painful parent,* an interfering parent (Eileen)<br>*[*They] made me feel as if I was being *a pain* (Michelle)<br>‘Oh, this mother is *a helicopter mother.’* (Michelle)<br>I’d have given anything to *drop her at the front gate* (Michelle)<br>I’d rather *sweep that under the carpet* (Mary)<br>I don’t want to be seen as *a helicopter parent* (Mary)<br>I’m trying not to be *the helicopter mother* (Eloise)<br>Calling them *helicopter parents* is unfair (Frances) |
| | Keeping parents at a distance | *A golden key* (Eileen)<br>You can *cross barriers* (Eileen)<br>Which *way/ avenue to go in* (Mary)<br>I’m *breaking new ground* (Mary)<br>*Called in to school* (Eileen)<br>*Going up to school* (Eileen)<br>*Went in to see the teachers* (Frances) |

## Appendix P: Conceptual Metaphors. Concerns for childs' wellbeing and wellbecoming

| Overarching theme | Subthemes | Key metaphors |
|---|---|---|
| Participants' concerns for their child's current well*being* and future well*becoming* | General expressions relating to child's anxiety related to academic pressure / classroom environment | It all just *goes over your head* (Eileen)<br>It must just *whirl around you* all day (Eileen)<br>They're *full on* all day (Eileen)<br>We're putting *no pressure on her* academically (Eileen)<br>It's just *the pressure that they put themselves under* (Eileen)<br>It's just *this pressure build-up inside their heads* (Eileen)<br>*Standing ground* (Mary)<br>A *meltdown* (Mary)<br>A *blow up* (Mary)<br>He *shut up shop* (Mary)<br>He had *given up* (Mary)<br>All that just *builds up* (Mary)<br>*The wheels were going to come off* (Mary)<br>[Learning support] is not *a perfect fit* (Mary)<br>This is *what we've got to work with* (Mary)<br>He was *falling through the net* (Mary)<br>*Everything falls apart* (Mary)<br>*Struggled* with learning (Frances)<br>An *alien language* (Frances)<br>*Fuelling* any anxiety (Frances)<br>*Making that anxiety grow* (Frances)<br>You knew that he wasn't dumb but just couldn't *get his answers out* on the paper (Frances)<br>It was stressful so *we dropped that subject* (Frances)<br>*The pressure* even, well from their school mates (Eloise)<br>*He had nothing. He just couldn't picture it* (Eloise)<br>You could *see her shrinking* (Michelle)<br>She will quickly feel overwhelmed and *shut down* (Eileen) |
| | Specific expressions relating to child's anxiety related to social issues | She didn't seem *to get other children* (Michelle)<br>She just didn't seem *to get along* (Michelle)<br>How can you not see that that is mean, *to leave one girl out?* (Michelle)<br>*She doesn't belong* (Michelle)<br>*Radar* for anyone that's different (Michelle) |

| **Overarching theme** | **Subthemes** | **Key metaphors** |
|---|---|---|
| | | *Phased out* of friendship groups (Michelle)<br>Not strong enough *to stand up* to the other girls (Michelle)<br>She would always get *thrown out* (Michelle) |
| | The importance of friendships | She doesn't want to do what the other girls are doing … *it's too hard* and she doesn't *get it* (Eileen)<br>*The playground can be tough* (Eileen)<br>*The rhythm of understanding* social etiquette (Mary)<br>*'Friendships' is huge* (Mary)<br>[Friends] wouldn't be *flooding through the door* (Mary)<br>*A safe place* in primary school (Frances)<br>*Safety in numbers* (Frances) |
| | Stigma attached to difference | *Square peg in a round hole* (Mary)<br>*Fish out of water* (Eileen)<br>'I don't want my classmates to know that I'm *struggling* to read it' (Eloise)<br>The other boys are going to *pick up on that* (Eloise)<br>I don't think there's *a bottom maths class,* so everybody knows, 'Oh, they're the ones who *struggle'* (Eloise) |
| | Negative teaching practices & teacher attitudes to inclusion | She just *whittled away* Rory's confidence (Eloise)<br>He just *lost his confidence* in everything (Eloise)<br>He was *very old school … cut and dried …*<br>*Press somebody's buttons until they explode and run away* (Mary)<br>Like not having *all the teachers on board* (Mary)<br>She was *standing over them* (Eloise)<br>I think she was very much *a tough love* (Eloise)<br>She was just *going through the motions* (Eloise)<br>She refused to *go with it* (Eloise)<br>Definitely not *a softie.* Definitely *tough love!* (Eloise)<br>I wouldn't *rave about* the learning support there (Eloise)<br>Trying to *wean him off ...* having too much assistance (Eloise)<br>They *weren't actually spending enough time* (Eloise)<br>The *level of abuse* from the other girls that they did expect her to put up with (Michelle) |

| Overarching theme | Subthemes | Key metaphors |
|---|---|---|
| | Positive teaching practices & teacher attitudes to inclusion | She's *in the mainstream* [ but] she's not working *on the same level* as the other kids (Eileen)<br>*Ear-marked* as needing some extra support (Frances)<br>No child is *new to him* (Eloise)<br>They were very *on top of* the things that they needed to be *on top of* (Eloise)<br>He's getting a great *level of support* (Eloise)<br>They knew she had ASD and they were really *on top of* what that meant for her (Michelle) |
| | School culture | *The School Family* (Eileen)<br>She's *comfortable* with learning support (Eileen)<br>Go somewhere *nurturing,* with a broad curriculum… *it ticked both boxes* (Eileen)<br>I have a very *positive vibe* about it (Eileen)<br>I think it's a very *gentle school* (Eloise)<br>There's nothing that the teacher *can grasp* (Michelle)<br>There's nothing for the teachers *to cling to* (Michelle)<br>Trying to *grab a handful of fog* (Michelle)<br>Talk about [inclusion] … doesn't *penetrate with these girls* (Michelle)<br>Schools can … *bring the parents on board* (Michelle) |
| | Concerns for wellbecoming | There will always be *a good spot* somewhere for Emily (Eileen)<br>The system's *set up* now, you've got to sort of have a certificate (Frances)<br>So he's not *completely scarred* by the experience (Eloise) |

# Appendix Q: Clustered themes - participants’ narratives

| Parents’ perception of links between school & child’s anxiety | | | | | | |
|---|---|---|---|---|---|---|
| | **Security in primary school** | **Stigma attached to learning issues** | **Impact of teaching practices** | **Systemic issues of high school** | **Anxiety felt in other aspects of life** | **decisions around high school** |
| **Mary** | Transition to high school made easier by elements of continuity & familiarity | Anxiety in meeting teacher’s expectations / completing assessment tasks | Disparity between IEP intentions and staff practices | The wheels fall off at the end of term - meltdowns & behavioural | Anxiety causing sleep difficulties at home; meltdowns at school | Other family members attend – perception that all schools have similar structures & require parental involvement & advocacy |
| **Eloise** | Security in small school & familiar surroundings | Struggling with Learning Issues – anxiety related to social stigma | Rejection of IEP The potentially negative impact of some teaching practices<br>Development of strengths by Principal reduced anxiety and heightened confidence | Too many commands are overwhelming | Anxiety in academic domain affecting other life domains Confidence “whittled away” , Stammer, sport & friends did not compensate | Active decision making to support wellbeing: Transition year – *finding his feet* socially and emotionally<br>Now “smooth sailing” |
| **Frances** | Primary school “a safe place”. “Safety in numbers” – social safety in groups. | The emotional toll of learning difficulties – sense of failure caused significant emotional distress<br>Forbes belief that he was the least intelligent in his class caused acute distress | Feeling different to peers – the stigma attached to learning difficulties. | Educators must consider which educational practices cause or exacerbate anxiety | Anxiety can pervade all aspects of child’s life and impact the whole family – camping trip, avoiding sleepovers<br>Anxiety caused Forbes to withdraw from his normal social activities but would not communicate – Frances needed to interpret his withdrawal | Active decision making to support wellbeing: Forbes’ anxiety (and learning issues) complicated decisions around high school choices<br>Change in schools related to anxiety |

| Parents’ perception of links between school & child’s anxiety | | | | | | |
|---|---|---|---|---|---|---|
| | **Security in primary school** | **Stigma attached to learning issues** | **Impact of teaching practices** | **Systemic issues of high school** | **Anxiety felt in other aspects of life** | **decisions around high school** |
| **Michelle** | Friendship groups at primary school provided “safe places” – can’t transfer to high school | Didn’t want to be a part of the Learning Support group | Literacy issues but less about learning & more about social issues | Could not learn nuanced social cues of adolescent girl groups – “sitting in circles” & talking | “Shrinking”/<br>“Creeping around school like subhuman creature” | Family connections & ritual both important to Kate<br>Active decision making to support wellbeing: Distance Education as response to anxiety |
| **Eileen** | Learning Support<br>Family provide security | Emily’s perception that other girls are unaware of her learning issues | “Terrified” at primary school, always unwell” because couldn’t complete homework | Emily will “shut down” if not working at own level/ pace | Acute anxiety affects every day life – distress over *60 Minutes* & night terrors as evidence of anxieties about school | Family experience with school, “nurturing place” with broad curriculum – paediatrician’s advice |