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A U S T R A L I A

**Square pegs in round holes: The mainstream schooling experiences of students
with an Autism Spectrum Disorder and their parents**

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Abstract

There has been an international movement towards inclusion and consequently an increasing number of children with Autism Spectrum Disorders (ASDs) attend mainstream schools. In recent years there has been a growth in cross-sectional research that seeks to understand the experiences of students with ASD in mainstream schools. This research indicates that students often experience bullying, a lack of understanding from teachers and peers and frequent suspensions and exclusions. To date there has been little research to explore the participation of students with ASD in mainstream school over time. There is a need to understand participation in mainstream school as a process over time that changes in response to the complex interplay of the individual and their environment. This will inform the development of strategies to better facilitate their participation across primary and secondary school.

This thesis aims to develop an understanding of participation in mainstream school over time from the perspective of students with ASD and their parents. The study uses a qualitative methodology and is underpinned by Life Course Theory, which recognises the dynamic interaction of individual and contextual factors and processes on life experiences. To investigate perspectives and experiences of participation in mainstream school semi-structured interviews were conducted with eight students with ASD aged 12-15 years and 11 parents. Parents were interviewed on two occasions and students were interviewed once, generating a total of 26 interviews. Retrospective interviews with parents were conducted to elicit their perspectives about their children's educational participation across primary and secondary school and their experiences of supporting their children's participation over time. Student interviews captured a snapshot of their perspectives on their current participation in mainstream schools. Thematic analysis of the interview data was undertaken and concepts from Life Course Theory were applied to the data to enable a deeper understanding of the themes of participation in mainstream school across the schooling years.

The findings of the study indicate that the majority of parents perceived that their children had restricted participation in mainstream schools and their educational trajectories were characterised by disruption. A minority had relatively stable academic participation trajectories, but still had difficulties with social participation. Furthermore, students experienced academic mismatch and standing out in mainstream schools. Parents universally experienced a perpetual battle to support their children's participation in mainstream schools over time. Parents and students actively tried to influence their participation but most perceived they had little control over their participation in mainstream schools. This indicated that the school environment had a significant and constraining

influence on their participation.

This thesis makes a contribution to knowledge about the participation of students with ASD in mainstream school by incorporating the perspective of students with ASD and their parents and more so, by considering participation across schooling years as a whole. It also makes a contribution to methodological knowledge about doing inclusive research with young people with ASD.

A number of policy and practice recommendations are made, including the need for mainstream schools to accept greater responsibility for accommodating each individual student with ASD, and to encourage more meaningful involvement of parents and students in educational planning in order to improve their participation.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Publications during candidature

Harrington, C., Foster, M., Rodger, S., & Ashburner, J. (2013). Engaging young people with Autism Spectrum Disorder in research interviews. *British Journal of Learning Disabilities*, Advance online publication. doi: 10.1111/bld.12037

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A portion of this paper is incorporated into chapter four on the methodology of the thesis. Caitlin Harrington was responsible for conducting the study and preparing the manuscript for publication. Associate Professor Michele Foster, Professor Sylvia Rodger and Dr Jill Ashburner provided editorial advice on the manuscript.

Contributions by others to the thesis

No contributions by others.

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participation in this study would shed light on the challenges encountered by students with ASD in the mainstream education system and that this knowledge could be used to help other families of children with ASD to have a more positive experience. I hope this thesis does justice to their experiences and contributes to a better understanding of this important issue.

Keywords

Autism spectrum disorder, participation, inclusion, mainstream school, qualitative, life course theory.

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LIST OF ABBREVIATIONS

A4	Autism Aspergers Advocacy Australia
ABS	Australian Bureau of Statistics
ACARA	Australian Curriculum, Assessment and Reporting Authority
ADOS	Autism Diagnostic Observational Schedule
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
Aspect	Autism Spectrum Australia
AQ	Autism Queensland
BESD	Behavioural, Emotional and Social Difficulties
CADDRE	Centres for Autism and Developmental Disabilities Research and Epidemiology
CALD	Culturally and Linguistically Diverse
CARS	Childhood Autism Rating Scales
CDA	Children with Disability Australia
CDC	Centers for Disease Control and Prevention
DETE	Department for Education, Training and Employment
DEWR	Department of Education, Employment and Workplace Relations
DSM	Diagnostic and Statistical Manual of Mental Disorders
EAP	Education Adjustment Program
EQ	Education Queensland
HCWA	Helping Children With Autism
IAN	Interactive Autism Network

ICF	International Classification of Functioning, Disability and Health
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
II	Intellectual Impairment
IQ	Intelligence Quotient
KADI	Krug Asperger's Disorder Index
MSSWD	More Support for Students with Disabilities
NAPLAN	National Assessment Program – Literacy and Numeracy
NAS	National Autistic Society
NHMRC	National Health and Medical Research Council
NLSY	National Longitudinal Surveys of Youth
PCS	Picture Communication Symbols
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
PEAC	Partnerships between Education and the Autism Community
PEERS	The Program for the Education and Enrichment of Relational Skills
PEO	Person-Environment-Occupation
PLASN-R	Pan-London Autism Schools Network research partnership
QPPD	Queensland Parents for People with a Disability
SAS	Secret Agent Society
SEC	Special Education Class
SEED	Study to Explore Early Development
SEU	Special Education Unit
TAFE	Technical and Further Education

ToM	Theory of Mind
UNESCO	United Nations Scientific & Cultural Organisation
UQ	University of Queensland
WHO	World Health Organisation

CHAPTER ONE: INTRODUCTION

This thesis explores the participation of students with Autism Spectrum Disorder (ASD) in mainstream school over time. It is proposed that their participation in mainstream school is shaped by a complex interaction of individual and contextual factors. In order to more adequately respond to and improve the participation of students with ASD in mainstream school, it is necessary to understand their participation over the course of their schooling. Therefore this study aims to understand from the perspectives and experiences of students with ASD and their parents the participation of students with ASD in mainstream school over time.

The origins of this study can be traced back to the candidate's work as a social worker at Autism Queensland (AQ), a not-for-profit organisation that provides education & therapy services for children with ASD throughout Queensland, Australia. In this role the candidate provided support to the parents and siblings of the children with ASD who were attending one of two AQ centres in Brisbane. The candidate observed a number of parents reporting that their child with ASD was experiencing multiple barriers to their participation in mainstream school. Parents told of schools failing to modify the curriculum to meet their children's needs; repeatedly calling them in during the day to collect their child following behavioural incidents; reducing the normal hours of attendance for their child and frequently suspending them. Parents were distressed by their children's experiences of exclusion and its negative impact on their own lives in terms of their employment, relationships, physical and mental health. This piqued the candidate's interest in this area and led her to investigate whether this was a common experience for other students with ASD and their families. A brief canvas of the extant literature revealed students were having a similar experience of exclusion in the United Kingdom (Barnard, Broach & Prior, 2002; Batten, Corbett, Rosenblatt, Withers & Yuille, 2006; Humphrey & Lewis, 2008).

1.1 RATIONALE FOR THE STUDY

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder characterised by persistent difficulties in social communication and social interaction and restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association [APA], 2013). Epidemiological evidence indicates there are increasing numbers of people being diagnosed with ASD worldwide (Fombonne, 2003). With the move towards the inclusion of students with disabilities in mainstream schools, increasing numbers of children with ASD attend mainstream schools. However, international and Australian research indicates that students with ASD encounter

a range of barriers to their participation in mainstream schools including difficulty enrolling in their local mainstream school (McDonald, 2010; Lilley, 2012); teachers who lack an understanding of ASD (Autism Spectrum Australia [Aspect], 2012; Barnard et al., 2000; Batten et al., 2006; Brewin, Renwick & Schormans, 2008; Jindal-Snape, Douglas, Topping, Kerr & Smith, 2005; Kidd & Kaczmarek, 2010; Reid, 2011); and a lack of modification to the curriculum, social and physical environment (Batten et al., 2006; Reid, 2011; Stewart, 2012). Furthermore, research indicates that students with ASD experience bullying throughout their mainstream schooling and report higher levels of bullying compared with students with other special needs and typically developing students (Humphrey & Symes, 2010; Jones & Frederickson, 2010; Wainscot, Naylor, Sutcliffe, Tantam & Williams, 2008) and lower levels of social support (Humphrey & Symes, 2010). Students have experienced serious, negative impacts as a result of bullying including: disruptions to educational progress (Batten et al., 2006; Reid & Batten, 2006), reduced self-esteem and social skills (Batten et al., 2006), mental health difficulties (Batten et al., 2006; Cappadocia, Weiss & Pepler, 2012; Hebron & Humphrey, 2012; Penney, 2013; Zablotsky, Bradshaw, Anderson & Law, 2013), and suicidal feelings and self-harming behaviour (Batten et al., 2006).

Research also indicates that some students with ASD under-achieve relative to their cognitive abilities in mainstream schools (Ashburner, Ziviani & Rodger, 2008). They also have high rates of absenteeism, suspension and exclusion from school (Barnard et al., 2000; Batten et al., 2006; Osler & Osler, 2002; Reid, 2011). Taken together, these findings suggest that instead of receiving an inclusive education that meets their needs in mainstream schools, students with ASD often experience exclusion. In response to this, parents of children with ASD have been increasingly compelled to home-school their children with ASD (Anonymous, 2007; Batten et al., 2006; Hurlbutt, 2011; Kidd & Kaczmarek, 2010; McConnell, 2006; McDonald, 2010; Parsons & Lewis, 2010; Reid, 2011). This places additional pressure on parents and has financial implications for their families if they are forced to relinquish employment in order to undertake home schooling (McDonald, 2010).

There has been a call for more qualitative research in the field of ASD generally (Bolte, 2014) and specifically for qualitative research about educational participation from the perspective of students with ASD in order to better understand how to support their participation in mainstream schools (Connor, 2000; Carrington & Graham, 2001; Osler & Osler, 2002; Humphrey & Lewis, 2008; Humphrey & Parkinson, 2006). It is evident that the few studies that have elicited the perspectives of students with ASD have enriched the empirical literature by: (a) adding their unique perspective on participation in mainstream schools (Poon, Soon, Wong, Kaur, Khaw et al., 2012), (b) by

uncovering educational practices that operate to exclude them (Osler & Osler, 2002), and (c) by informing the development of practical strategies to support their educational participation (Humphrey, 2008). Despite calls for more research there continues to be a lack of in-depth research that incorporates the perspectives of students with ASD about their perceptions and experiences of participation in mainstream school. For example, Falkmer, Granlund, Niholm and Falkmer (2012, p. 192) recently noted “knowledge of their perception of participation and to what extent they want to participate in the school context is still limited, so more knowledge is needed in order to develop inclusive mainstream schools”. Consequently, students remain excluded not only from mainstream education, but often from research. It is therefore timely to conduct inclusive research, which directly listens to their voices and seeks to understand their perceptions and experiences of participation.

Parents of children with ASD play a crucial role in the mainstream education of students with ASD (McDonald, 2010). Although a large number of extant studies have elicited parents' perspectives on the mainstream education of their children with ASD (Barnard et al., 2000; Batten et al., 2006; Kasari, Freeman, Bauminger & Alkin, 1999; Starr, Foy & Cramer, 2011; Starr, Foy, Cramer, & Singh, 2006; Waddington & Reed, 2006; Whitaker, 2007), most of these have used quantitative questionnaire designs that do not capture parents' lived experience of supporting their children's education or the impacts on their lives. There is a paucity of qualitative research focused on parents' lived experience of supporting their children's participation (McDonald, 2010). Consequently, there is a need for more qualitative research that captures parents' perceptions and experiences of supporting their children's participation in mainstream school.

Despite a recent growth in cross-sectional research that seeks to understand the experiences of students with ASD in mainstream schools (See Hay & Winn, 2005; Humphrey & Lewis, 2008; Poon et al., 2012; Saggers, Hwang & Mercer, 2011) the significant gap in empirical knowledge relates to the participation of students with ASD in mainstream school across schooling years, including primary and secondary years, from the perspective of students with ASD and their parents. Addressing this knowledge gap will provide a more complete, rather than single point in time, empirical picture of participation, which can also form the basis for more comprehensive policy and practice initiatives.

The significance of this study is in its use of a qualitative approach underpinned by Life Course Theory (Elder & Giele, 2009) to contribute to an in-depth understanding of the participation of students with ASD in mainstream school over time from the perspective of students with ASD and

their parents. This knowledge can be used to inform and assist educators and policy makers about methods for supporting the participation of students with ASD throughout their education. By incorporating the voices of students with ASD and developing creative data collection strategies that maximise their participation, this study will also contribute to methodological knowledge about inclusive research with students with ASD.

1.2 CONTEXT OF THE STUDY

As background to this study on the perceptions and experiences of students with ASD and their parents about participation in mainstream school over time in Queensland, Australia, this section describes the context of the research. Firstly, a brief description of ASD is provided, including characteristics, prevalence, aetiology, diagnosis and the education of school-aged children with ASD. Then, the international movement towards ‘inclusion’ in education is discussed. Finally, the Australian and Queensland schooling system are outlined.

1.2.1 Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder (Volkmar, 1998). Diagnosis of ASD requires impairments in three core areas: social interaction, communication and inflexible thinking and behaviour (Wing, 1996). Recently revised diagnostic criteria for ASD are outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013). Under the previous system (DSM-IV) ASD had subcategories including: Autistic Disorder, Asperger’s Syndrome, Retts Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS) (APA, 2000). Under the new DSM-5 guidelines the broad term Autism Spectrum Disorder is used and the subcategories no longer exist (APA, 2013). In the DSM-5 ASD is characterised by persistent difficulties in social communication and social interaction and restricted, repetitive patterns of behaviour, interests or activities (APA, 2013). While ASD has core characteristics, there is wide variability in the manifestation of these characteristics in each individual (Jordan, 2005).

Sensory processing issues are an associated feature of ASD (Ayres & Tickle, 1980; Bagnato & Neisworth, 1999; Ermer & Dunn, 1998; Kientz & Dunn, 1997; Smith-Myles et al., 2004). They may include: over-responsivity in which an individual experiences distress or displays an exaggerated negative response to sensory input, sensory under-responsivity, in which an individual may seem to be unaware of, or slow to respond to, a stimulus that would normally be expected to elicit a response or sensory-seeking behavior in which an individual exhibits an unusual craving for,

or preoccupation with certain sensory experiences (Ben-Sasson, 2008). Fine and gross motor coordination problems are another associated feature of ASD (Fournier, Hass, Naik, Lodha & Cauraugh, 2010; Green et al., 2009; Hilton, Zhang, Whilte, Klohr & Constantino, 2012).

Prevalence and incidence

The prevalence of ASD is contested in the literature (Roberts & Prior, 2006). In Australia it is estimated that 1 in 160 people have ASD (MacDermott, Ridley, Glasson & Wray, 2006). Higher prevalence rates have been reported in other countries. For example, in the United States prevalence in one study was estimated to be 1 in 88 (in a total population cohort 337,093 children aged 8 years) (Autism and Developmental Disabilities Monitoring Network, 2012) and 1 in 68 (in a total population cohort 363,749 children aged 8 years) (Autism and Developmental Disabilities Monitoring Network, 2014). In the United Kingdom, ASD prevalence was measured at 1 in 116 (in a total population cohort of 56 946 children aged 9-10 years) (Baird et al., 2006). The number of children diagnosed with ASD has increased over the past four decades (Baron-Cohen et al., 2009; Elsabbagh et al., 2012). There is debate about whether there has been a true increase in incidence of ASD (Williams et al., 2014a). Taking the evidence into account, the increase is not likely to be the result of a true increase in prevalence. It is argued to be the result of more sensitive diagnostic tools, widening diagnostic criteria (Baird et al., 2006; Baron-Cohen et al., 2009; Charman, 2013) and greater awareness of ASD in the general and professional community (Elsabbagh et al., 2012; Williams et al., 2014a).

Research indicates that ASD is more prevalent in males than females with a male to female ratio of 4.3:1 (Fombonne, 2003). Autism Spectrum Disorder is associated with other medical conditions such as intellectual impairment and epilepsy (Fombonne, 2003). Recent data from the US Centre of Disease Control and Prevention (Autism and Developmental Disabilities Monitoring Network, 2014) show that out of the 4,140 children with ASD in the sample, 31% of children with ASD were classified as having Intelligence Quotient (IQ) scores in the range of intellectual disability ($IQ \leq 70$), 23% in the borderline range ($IQ = 71-85$), and 46% in the average or above average range of intellectual ability ($IQ > 85$).

Aetiology

To date, no common aetiology for ASD has been identified (Rutter, 2005; Williams et al., 2014a). Evidence suggests multiple causes including genetic and environmental factors (Chaste & Leboyer, 2012; Rutter, 2005). A number of large-scale investigations into ASD aetiology are currently

underway. The Autism Phenome Project at the UC Davis MIND Institute is studying children with ASD who are two to three and a half years of age and comparing this data with children with typical development. Lines of investigation include: environmental exposures, genetics, immune system functions and brain structures with the aim of distinguishing phenotypes of ASD (UC Davis MIND Institute, 2014). The Centres for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network, are currently working on the Study to Explore Early Development (SEED) which is the largest study in the United States to help identify factors that may put children at risk for ASD and other developmental disabilities (Centers for Disease Control and Prevention [CDC], 2014). Finally, the Brain Bank for Autism and Related Developmental Research in the United Kingdom was set up in 2008 and is a depository for post-mortem brain tissue and enables research into the biological origins of ASD (Brain Bank for Autism, 2014).

Diagnosis

In Australia the diagnosis of ASD, and the specialists involved, vary across the States and Territories (Williams et al., 2014b). In Queensland, the site of this study, a diagnosis of ASD is typically made by either a paediatrician or a child psychiatrist (Department of Communities, Child Safety and Disability Services, 2012). Most of these specialists use multiple sources of information (parents and teachers, allied health professionals) and most incorporate some observational assessment of the child themselves (Skellern, McDowell & Schluter, 2005). Some use ASD-specific diagnostic tools such as the Childhood Autism Rating Scales 2nd edition (CARS) (Schloper, Reichler & Renner, 1986) or the Autism Diagnostic Observational Schedule- Generic (ADOS-G) (Lord et al., 2000). However, there are currently no nationally recognised diagnostic procedures or uniform guidelines and accreditation of specialists providing diagnosis and treatment for those with ASD is only now emerging in select states such as Victoria (Williams et al., 2014b). Under the recently established Cooperative Research Centre for Living with Autism Spectrum Disorders (a national, cooperative research effort focussed on ASD funded by the Australian Government, universities and industry partners which takes a "whole-of-life" approach to ASD focussing on three core research programs: diagnosis, education and adult life) there is a proposal to develop a graduate qualification in autism diagnosis and assessment (Williams et al., 2014b).

Education of school-aged students with ASD

Students with ASD are heterogeneous and have different learning styles, preferences, interests and abilities. It is widely recognised that there is no one-size-fits-all approach to their education,

therefore individualised education programs are required to address students' unique needs (Guldberg et al., 2011; Iovannone, Dunlap, Huber, & Kincaid, 2003; Roux, Graham & Carrington, 1998). Core elements of education widely reported in the literature include:

1. A modified curriculum (Lynch & Irvine, 2009) that incorporates visual supports (Harrower & Dunlap, 2001; Humphrey, 2008; Konza, 2005; Leach & Duffy, 2009; Roberts & Prior, 2006), strengths and special interests (Charman et al., 2011; Konza, 2005; Roux et al., 1998) and explicitly teaches life skills (Charman et al., 2011), communication and social skills to children (Humphrey, 2008; Iovannone et al., 2003; Konza, 2005; Leach & Duffy, 2009). This includes teaching the 'hidden curriculum', which refers to the unwritten social rules and expectations of behavior that are embedded in society but not explicitly taught (Humphrey, 2008; Konza, 2005; Simpson, de Boer-Ott & Smith-Myles, 2003).
2. Predictability and routine and advance notice of any changes to the school schedule (Humphrey & Lewis, 2008; Lynch & Irvine, 2009; Roberts & Prior, 2006; Roux et al., 1998).
3. A functional approach to challenging behaviour - this involves analysing the behaviour to determine its underlying function and teaching the child to replace the maladaptive behaviour with a more appropriate behaviour (Iovannone et al., 2003; Leach & Duffy, 2009; Roberts & Prior, 2006).
4. Transition support - for both daily transitions such as changes between classes and yearly transitions such as entry to school, secondary school and exiting secondary school (Adreon & Stella, 2001; Konza, 2005; Roberts & Prior, 2006; Stoner, Angell, House & Bock, 2007).
5. Multi-disciplinary and multi-agency collaboration to ensure services for children with ASD are coordinated and address their academic, social, behavioural and physical needs (Charman et al., 2011; Guldberg et al., 2011; Jones et al., 2008; Lynch & Irvine, 2009; Parsons et al., 2011; Simpson et al., 2003).
6. Home-school collaboration and parental involvement in educational decision-making (Charman et al., 2011; Eldar, Talmor & Wolf-Zukerman, 2010; Iovannone et al., 2003; Jones et al., 2008; Lynch & Irvine, 2009; Simpson et al., 2003; Roberts & Prior, 2006; Waddington & Reed, 2006).
7. Environmental modifications – such as structuring the physical environment to minimise distraction and respond to students' sensory needs and preferences (Deris & Di Carlo, 2013; Leach & Duffy, 2009; Roux et al., 1998).

8. Knowledgeable teachers who are trained in ASD (Charman et al., 2011; Humphrey, 2008; Jones et al., 2008; Jordan, 2008; Roux et al., 1998) and can adapt their instructional methods, for example by being more explicit in their use of language in the classroom (Humphrey, 2008; Jones et al., 2008; Jordan, 2008; Roux et al., 1998).

It is also acknowledged that individuals with ASD should be consulted about their educational needs (Guldberg et al., 2011) and that there should be high ambitions for students with ASD to reach their full potential (Charman et al., 2011). Also, there should be involvement of peers in supporting students with ASD (Harrower & Dunlap, 2001; Roberts & Prior, 2006) and improved peer awareness of ASD (Humphrey, 2008). Furthermore, there should be recurrent evaluation of inclusive practices (Simpson et al., 2003). Authors argue that integrating these core elements into mainstream education will ensure an appropriate and effective education for all students, not just those with ASD (Jordan, 2008; Lynch & Irvine, 2009).

Although these core elements are widely reported in the literature, a recent international review of the evidence on best practice in educational provision for children with ASD by Parsons et al. (2011) acknowledged:

Overall, there remains a notable lack of empirical evidence to inform practice and policy with regard to what ‘best practice’ means in real-world classrooms and how ‘joined-up working’, as well as effective and appropriate practice, can best be achieved for autism-specific schools and services. (p. 61)

Students with ASD may, therefore, not be receiving an education in mainstream schools consistent with best practice as outlined in the literature (Lynch & Irvine, 2009). This is likely to have negative implications for their participation in mainstream schools.

There is continued debate about whether mainstream school or an ASD-specific placement is the best educational option for students with ASD (Roberts & Prior, 2006). Some academics, professionals and parents have questioned the appropriateness of fulltime placement of students with ASD in mainstream schools. For instance, Mesibov and Shea (1996) reviewed the literature and compared the benefits of specialised placement with those of mainstream placement. They concluded that: “the research literature on full inclusion and students with autism is so limited that it provides an insufficient foundation for empirically based decisions about the benefits of the approach for this group of students” (Mesibov & Shea, 1996, p. 342). Furthermore, in several studies in the United Kingdom, parents of children with ASD have expressed a desire for a range of

provision including mainstream schools, specialist provision within mainstream schools, special schools and ASD-specific schools (Batten et al., 2006; Reid, 2011; Waddington & Reed, 2006). In Queensland, there is currently a social movement of parents of children with ASD petitioning for fulltime ASD-specific schools on social mediums such as Facebook™ and Change.org. Many ASD professionals and research academics also argue for the need to maintain a range of provision to ensure all students with ASD have access to an educational environment that meets their unique needs (Batten et al., 2006; Eaves & Ho, 1997; Guldberg et al., 2011; McDonald, 2010; Mesibov & Shea, 1996; Parsons et al., 2011; Reid, 2011; Stewart, 2012; Williams White, Scahill, Klin, Koenig, & Volkmar, 2007), and in cases where this does not currently exist, to create local access to this range of provision (Batten et al., 2006; Reid, 2011; Stewart, 2012). Furthermore, Williams White et al. (2007, p. 141) assert that educational placements should be fluid and therefore “consideration should be given to both child characteristics (e.g., abilities and skills) and program characteristics (availability of supports and special services) over time as the child develops”.

Some academics, professionals and parents report benefits to the placement of students with ASD in mainstream schools. For example, Harrower and Dunlap (2001) reviewed research on effective strategies for including students with ASD in mainstream settings and reported that there were some positive outcomes in mainstream classrooms for some students with ASD. Furthermore, in some studies parents and teachers have reported a perceived benefit of including students with ASD with mainstream peers in improved social skills (Eldar et al., 2010; Osborne & Reed, 2011; Waddington & Reed, 2006) and positives for mainstream classmates such as learning tolerance and acceptance of difference (Plevin & Jones, 2000).

While the different placement options for students with ASD continue to be debated, the reality in Australia is that the number of students being educated in mainstream classrooms is increasing (Roberts & Prior, 2006) and in most jurisdictions students do not have the option to attend an ASD-specific school on a fulltime basis (Australian Advisory Board on Autism Spectrum Disorders, 2010). Thus there is a need to support their participation in mainstream schools. The Australian Government has recently implemented several programs to address the needs of school-aged students with ASD under the Helping Children with Autism (HCWA) package. This package includes the Positive Partnerships programme, which “aims to build partnerships between schools and families to improve the educational outcomes of students with autism spectrum disorder” (Department of Social Services, 2014). The programme provides professional development for teachers, leadership staff and other school staff to improve their understanding and skills in working with children with ASD. Workshops and information sessions are also held for parents and carers of

school-age students with ASD, to assist them to build working partnerships with their child's teachers, school leaders and other staff (Department of Social Services, 2014). Although this landmark program is a step in the right direction to supporting the needs of school-aged children with ASD and their families its programs have not yet created widespread change. For example, an evaluation of the professional development program for teachers indicates the program had only reached 1% of Australian teachers (Allen Consulting Group, 2010). This is of major concern as research indicates that parents of children with ASD perceive the teacher's understanding of ASD to be critical to their children's successful participation in mainstream schools (Jones et al., 2007; Renty & Roeyers, 2006; Wittemeyer et al., 2011).

1.2.2 ‘Inclusion’ in mainstream school

There has been an international movement towards the inclusion of children with disabilities in mainstream schools for several decades. The origins of this movement can be traced back to the principle of ‘normalisation’ which emerged in the 1960’s and involved giving people with disabilities access to everyday life conditions which were as close as possible to the norms of the mainstream of society (Foreman & Arthur-Kelly, 2008). Several international conventions have also been influential as they explicitly state the rights of children with disabilities to be educated in mainstream schools. The *Salamanca Statement and Framework for Action on Special Needs Education* (United Nations Scientific & Cultural Organisation [UNESCO], 1994) decreed that every child has the fundamental right to education. Article 2 of the Statement proclaimed the need for an inclusive orientation:

Those with special educational needs must have access to regular school which should accommodate them within a child-centred pedagogy capable of meeting these needs; Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all... (UNESCO, 1994, pp. viii-ix).

More recently, the *Convention on the Rights of Persons with Disabilities* (UNESCO, 2007) has provided explicit support for inclusive schooling under Article 24—Education: “States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels...”. (p. 17)

Many western countries have legislated the right for students with disabilities to attend mainstream

schools. For example, in the United Kingdom the *Special Education Needs and Disability Act 2001*, legislated that children with special educational needs should receive their education in mainstream schools. In the United States the *Education for All Handicapped Children Act 1975* mandated free, appropriate public education to all children with disability. In 1990, this Act was amended and renamed the *Individuals with Disabilities Education Act* (IDEA). The Act requires public schools to develop an Individualised Educational Program (IEP) for each student in consultation with their parents, which describes how the student's disability affects their participation and the modifications that will be made by the school to support their participation (U.S. Department of Education, 2013).

In Australia, the right for students with disabilities to attend mainstream education is enshrined in the *Disability Discrimination Act 1992* (Cth). The Act states: “it is unlawful for an educational authority to discriminate against a person on the grounds of the person's disability by refusing or failing to accept the person's application for admission as a student” (Commonwealth of Australia, 1992, p. 23). A person with disability is able to apply for enrolment in an education institution “on the same basis” as a prospective student without disability. Furthermore, education providers are required to make “reasonable adjustments” to ensure students with disability are included unless it poses “unjustifiable hardship” on the provider (Commonwealth of Australia, 1992).

The *Disability Standards for Education 2005* (Cth) has further clarified and elaborated the legal obligations of Australian education providers. The Standards specify that education and training should be made accessible to students with disabilities in the following areas: enrolment; participation; curriculum development, accreditation and delivery; student support services; and the elimination of harassment and victimisation. The Standards apply to Government and non-government providers in all education sectors including pre-school, school, vocational education and training, higher education and adult and community education (Commonwealth of Australia, 2005). A recent review of the Standards has found, however, that they are not being met in practice (Department of Education, Employment and Workplace Relations [DEEWR], 2012). The review found that there was a lack of awareness about the Standards across the education sector and many schools failed to comply with the Standards (DEEWR, 2012). It concluded that students with disabilities still cannot enrol and participate in education ‘on the same basis’ as typically developing students (DEEWR, 2012). Another recent report by the National People with Disabilities and Carer Council (2009) on the experiences of people with disabilities and their families in Australia provides further evidence of the barriers to participation for students with disabilities in mainstream schools. It reported:

The education system continues to fail to respond to the needs of students with disabilities and, as a result, these students continue to lag behind on a range of attainment indicators...the results are not a reflection of a lack of ability of students but of the failure of the system to meet their individual needs. (National People with Disabilities and Carer Council, 2009, p. 47)

Although the right for students with disabilities to attend mainstream schools is legislated in Australia and the term inclusion has been adopted into educational policy, in general there has been a tendency to oversimplify the concept of inclusion and the way it is enacted in school settings. For example, inclusion in mainstream schools is often interpreted as simply a matter of relocating students with disabilities to mainstream school contexts and allocating resources to address their special educational needs (Booth & Ainscow, 1998; Lynch & Irvine, 2009; Slee, 2006). The focus is thus on fitting students into an unchanged system, which fails to address the factors within schools and broader society that act as barriers to learning and participation for students (Booth & Ainscow, 1998; Bourke & Carrington, 2007; Petrou, Angelides & Leigh, 2009; Slee, 2006). True inclusion views diversity as the norm (Ferguson, 1995) and as noted by Booth and Ainscow (2002) it involves “restructuring the cultures, policies and practices in schools so that they respond to the diversity of students in the locality [and] increasing the participation of students in, and reducing their exclusion from, the curricula, cultures and communities of local schools”. (p. 3)

1.2.3 The Australian school system

School education is primarily a state responsibility in Australia (Forlin & Forlin, 1998). State and Territory governments have responsibility for the delivery of government school education but schools are also operated by non-government education authorities, including Catholic education commissions and independent school authorities (Department of Education, 2013). The age of schooling commencement varies across the Australian States and Territories. Schooling is compulsory from six years of age in all States and Territories except for Tasmania where it is five years (Australian Curriculum, Assessment and Reporting Authority [ACARA], 2013). The first year of school is called different names in each state including: kindergarten, preparatory, transition and pre-primary. All Australian schools consist of primary and secondary schools. The years included in primary and secondary also vary across the States and Territories. In the majority of states (New South Wales, Victoria, Tasmania, the Northern Territory, and the Australian Capital Territory) primary school includes a preparatory year through to year six and secondary school includes year seven to twelve. In South Australia, and Western Australia and Queensland, primary

school includes a preparatory year through to year seven and secondary school includes year eight to twelve. The minimum school leaving age also varies, but in most States and Territories it is 17 years old (ACARA, 2013). The Australian school year runs from late January to mid-December. It is divided into two semesters, with two terms in each. Students generally have one teacher for each year in primary school and attend one classroom. In secondary school students generally have multiple subject teachers and change classrooms throughout the day for each subject.

1.2.4 The Queensland school system

In Queensland students may be enrolled in a state (called Education Queensland and run by the Department of Education, Training and Employment [DETE]), Catholic (run by Catholic Education) or an independent school (non-government schools governed and managed at the individual school level). There are also publically funded special schools, which are state schools that solely provide special education (Education Queensland, 2014). They cater for students with intellectual disability and/or multiple disabilities (Education Queensland, 2014). Distance education and hospital-based programs are provided to students unable to attend mainstream schools due to geographical or medical reasons (Education Queensland, 2014).

There are no full-time ASD-specific schools for students with ASD in Queensland. The sole ASD-specific education provider for school-aged children with ASD is AQ, a not-for-profit organisation that provides specialised education, therapy and support services for people with ASD and their families. Autism Queensland (AQ) has two accredited, independent schools delivering ASD-specific education and therapy programs to children diagnosed with ASD between prep and 18 years of age (AQ, 2014). Centre-based early intervention programs are also provided for children with ASD below the age of 4½ years. The policy of AQ is that students attend an AQ placement part-time for a period of one or two years concurrently with a mainstream school placement, after which they are expected to return fulltime to mainstream school. Students with ASD can access a part-time placement at one of two AQ centres in Brisbane - Brighton or Sunnybank for a period of two years on a fee-for-service basis. However, the availability of these placements is limited by waiting lists, cost and geographical accessibility (J. Ashburner, personal communication, 28th April, 2014).

A range of support is provided to students with disabilities in Queensland schools with the intent of improving their participation. In state and catholic schools, this includes an Education Adjustment Program (EAP), which is a process for identifying a student's impairment and the associated activity limitations and participation restrictions, which require significant education adjustments

under one or more of six EAP disability categories. It involves the development of an EAP profile, which describes the adjustments that are made to assist the participation of students with disabilities (Education Queensland, 2014). However, as has been pointed out by Bourke (2010, p. 187), the EAP process is problematic as it reinforces the perception that “disability is a deficit to be identified within the student” and the adjustment process requires the teacher to adapt the ‘normal’ curriculum instead of developing curriculum and pedagogy appropriate to all students.

Students with disabilities may also have an Individual Education Plan (IEP) developed on a six monthly basis by their teacher and parents to identify individual learning goals and strategies to meet these goals (Education Queensland, 2014). However, IEPs are not compulsory for school-aged children (Education Queensland, 2014). There are also Special Education Programs (SEPs), which refer to a clustering of specialist teachers who assist classroom teachers in the development and delivery of the students' educational program (Education Queensland, 2014). Additionally, there is access to support personnel including guidance officers, support teachers (literacy and numeracy), speech-language pathologists, behaviour support teachers, nurses, teacher aides, chaplains, specialist teachers (disability specific), physiotherapists and occupational therapists. However, often specialist teachers and therapists are not based on-site in schools, but rather service a large number of schools within a region (Education Queensland, 2014). Therefore students with disabilities may have limited access to specialists at their school.

Although schools in Queensland provide supports to students with disabilities and have inclusive education policies, which are intended to guide their operations, several studies have revealed that there continue to be significant barriers to the participation of students with disabilities in mainstream schools in Queensland. For example, a review of inclusive practices in Queensland schools by the Ministerial Taskforce on Inclusive Education (2004) acknowledged that:

Some core viewpoints and practices remain that hinder the provision of quality curriculum and pedagogy for students with diverse learning needs. Some of these represent the incomplete professional development of the workforce, while others are related to the belief that there is insufficient support to enable effective education for students in regular classes.
(p. 10)

More recently, Queensland Parents for People with a Disability (QPPD, 2011) a state-wide advocacy organisation surveyed 179 parents of children with disabilities, and held focus group discussions with a further 25 participants on their experiences of inclusive education in Queensland.

Parents in the study reported that their children experienced barriers to enrolment in their local mainstream school, spent less than half the school day in the mainstream classroom, with the rest spent in a special education program and a significant portion did not follow the same curriculum as their mainstream peers (QPPD, 2011). Consequently it was concluded: “parents cannot yet feel confident that inclusive policy is being put into practice in all Queensland schools” (QPPD, 2011, p. 2).

To date, there has been limited research in Queensland from the perspectives of students with ASD and/or their parents about their experiences in mainstream schools (see Carrington & Graham, 2001; Hay & Winn, 2005; Saggers et al., 2011) and the few studies that have been conducted have tended to focus on general educational issues rather than specifically on participation. Thus there is a need for an in-depth study that explores the perspectives and experiences of students with ASD and their parents in relation to their participation in mainstream school in Queensland.

1.3 STRUCTURE OF THE THESIS

This thesis is divided into nine chapters. An overview of each chapter will now be provided.

Chapter Two: Literature Review

This chapter provides an overview of the key literature that informs the thesis. A broad range of quantitative and qualitative research is reviewed thematically. It is noted that although there appears to be an extensive literature base in relation to students with ASD in mainstream schools, very few studies have focused on their participation in mainstream school. It is also demonstrated that there is a paucity of research to assist understanding of the participation of students with ASD in mainstream school over time. Further, the review indicates a lack of qualitative research focused on the lived experiences of parents of children with ASD about their role in supporting their children’s education in mainstream school across the school years. Thus the need for a qualitative study of the perceptions and experiences of students with ASD and their parents about participation in mainstream school over time is established.

Chapter Three: Conceptual Framework

This chapter discusses Life Course Theory (Elder & Giele, 2009) as the conceptual framework in this study to conceptualise the participation of students with ASD in mainstream school over time. The key tenets of Life Course Theory are outlined, with reference to how these tenets are applied in this thesis. It is demonstrated that Life Course Theory assists in understanding participation over time by drawing attention to transitions and turning points in students’ educational trajectories and

the issues of timing, the interactions between structure and agency, the linked lives of parents and children and the potential for cumulative processes.

Chapter Four: Methodology

The methodological approach employed in this study is described in Chapter four. Based on the review of the literature in chapter two and consistent with the conceptual approach outlined in chapter three a qualitative approach was deemed most appropriate for understanding the perceptions and experiences of students with ASD and their parents about participation in mainstream school over time. The research design entailed repeat semi-structured interviews with eleven parents of children with ASD followed by a single semi-structured interview with eight students with ASD. Innovative strategies were used during the interviews to enhance data collection such as participation trajectory grids and visual supports and the usefulness of these strategies is discussed in this chapter. The framework for thematic analysis developed by Braun & Clarke (2006) was employed to identify the central themes of participation related to parent perceptions and experiences and student experiences of participation. The chapter also discusses the rigour of the study and concludes with a critical reflection on the pertinent ethical issues.

Chapter Five: Parent perceptions of student participation across the schooling years

This chapter is the first of four findings chapters. It provides insight into how parents perceived and made sense of their children's participation in mainstream school across the schooling years. Three themes are identified 'restricted participation', 'variable impact of school staff' and 'turning points'. These are then discussed with reference to the extant literature.

Chapter Six: The participation trajectories of students with ASD

In this second findings chapter, the participation trajectories of the students with ASD are described. It identifies two participation trajectory types: 'a disrupted participation trajectory' and a 'relatively stable academic participation trajectory'. It then provides an in-depth description and analysis of two students' trajectories to exemplify these types.

Chapter Seven: Parent experiences of supporting their children's participation in mainstream school

In this third findings chapter, analysis of the parents' experiences of supporting their children's participation in mainstream school across the schooling years is presented. The principal theme identified was the 'perpetual battle'. The chapter provides insight into the significant involvement

of parents in their children's education, the strategies they used to attempt to influence their children's participation and how their lives were altered in the process.

Chapter Eight: Student experiences of participation in mainstream school

This final findings chapter further develops an understanding of the participation of students with ASD by presenting students current experiences of participation in mainstream school. Their experience was characterised by two themes: 'academic mismatch' and 'standing out'. The chapter also provides insight into how students attempted to influence their participation in school. The findings highlight that participation is facilitated when there is a good match between student characteristics, preferences and interests and the school environment.

Chapter Nine: Discussion and implications

This final chapter summarises the findings of the study and reviews them as a whole in relation to the extant literature around four central conclusions. The chapter then presents the implications for policy and practice. Methodological issues and strengths and limitations of the study are also discussed. The chapter concludes with the implications for future research.

CHAPTER TWO: LITERATURE REVIEW

In this chapter, the empirical literature on the participation of students with ASD in mainstream schools is synthesised and appraised, with an emphasis on assessing the research on their participation in mainstream school over time. Additionally, literature about parents' perceptions and experiences of supporting their children's participation in mainstream school is reviewed. The review establishes the importance of investigating the perceptions and experiences of students with ASD and their parents about participation in mainstream school over time.

2.1 SCOPE OF THE REVIEW

The aim of the literature review is to develop an understanding of the current state of knowledge about the participation of students with ASD in mainstream schools. The review includes empirical research papers spanning the period between 1999 and 2014. The body of research on students with ASD in mainstream schools is diverse in terms of country of origin, the focus and the methodologies used. The majority of the literature originated from northern Europe, particularly the United Kingdom (Barnard et al., 2000; Batten et al., 2006; Connor, 2000; Humphrey & Lewis, 2008; Jones & Frederickson, 2010; Parsons, Lewis & Ellins, 2009; Reid, 2011; Renty & Roeyers, 2006; Stewart, 2012; Tissot & Evans, 2006; Tobias, 2009; Waddington & Reed, 2006; Watson, 2009; Whitaker, 2007; Wittemeyer et al., 2011) followed by the United States (Interactive Autism Network [IAN], 2010; Kasari et al., 1999; Scuitto, Richwine, Mentrikoski & Niedzwiecki, 2012; Stoner et al., 2005; Stoner & Angell, 2006), Canada (Brewin et al., 2008; Penney, 2013; Starr et al., 2001; Starr et al., 2006; Starr & Foy, 2010), Australia (Carrington & Graham, 2001; Hay & Winn, 2005; Lilley, 2012; McDonald, 2010; Saggers et al., 2011), a single study in Singapore (Poon et al., 2012), and Sweden (Falkmer et al., 2012).

The extant research has been diverse in its focus. A numbers of studies have focused on the perceptions and experiences of students with ASD and/or their parents in mainstream schools related to their 'inclusion' (Batten et al., 2006; Reid, 2011; Hay & Winn, 2005), 'school experiences' (Poon et al., 2012), 'quality of life' (Brewin et al., 2008), 'effective education' (Jindal-Snape et al., 2005), 'school-related issues' (Penney, 2013) and 'school-related challenges' (Scuitto et al., 2012). Only three papers have focused specifically on the participation of students with ASD in mainstream schools (Falkmer et al., 2012; Humphrey & Lewis, 2008a; Saggers et al., 2011). A large number of studies have also focused on understanding the social inclusion of students with ASD, for example their social networks or experiences of bullying at school (Bauminger, Shulman

& Agam, 2003; Bauminger & Kasari, 2000; Calder, Hill & Pellicano, 2012; Chamberlain, Kasari & Rotheram-Fuller, 2007; Chen & Swartz, 2012; Humphrey & Symes, 2010a; Humphrey & Symes, 2010b; Humphrey & Symes, 2011; Jones & Frederickson, 2010; Locke, Ishijima, Kasari & London, 2010; Ochs, Kremer-Sadlick, Solomon & Gainer Sirota, 2001; Symes & Humphrey, 2012; Wainscot et al., 2008).

The diversity of terms used makes direct comparison of the literature difficult. It is necessary to draw a distinction here between the concept of participation and inclusion as these concepts are central to this thesis and the terms can become conflated. Participation refers to the active engagement of students in the academic and social activities of mainstream schools alongside their peers and a sense of belonging (Booth & Ainscow, 2002). In contrast, inclusion refers to a broader process of valuing student diversity and “increasing the participation of students in, and reducing their exclusion from, the cultures, curricula and communities of local schools [and] restructuring the cultures, policies and practices in schools so that they respond to the diversity of students in the locality” (Booth & Ainscow, 2002, p. 3).

In much of the research, questionnaire methods have been used (Barnard et al., 2000; Batten et al., 2006; IAN, 2010; Kasari et al., 1999; Parsons et al., 2009; Reid, 2011; Renty & Roeyers, 2006; Stewart, 2012; Starr et al., 2001; Starr et al., 2006; Tissot & Evans, 2006; Waddington & Reed, 2006; Watson, 2009; Whitaker, 2007; Wittemeyer et al., 2011). Semi-structured interviews have also been used in a number of studies (Carrington & Graham, 2001; Connor, 2000; Humphrey & Lewis, 2008; Humphrey & Symes, 2010; Brewin et al., 2008; Jindal-Snape et al., 2005; Lilley, 2012; McDonald, 2010; Penney, 2013; Saggers et al., 2011; Scuitto et al., 2012). Focus groups have been used in several studies (Hay & Winn, 2005; Tobias, 2009; Waddington & Reed, 2006) and observations were also used in two studies (Ochs et al., 2001; Humphrey & Symes, 2011).

2.2 THE PARTICIPATION OF STUDENTS WITH ASD IN MAINSTREAM SCHOOL

Despite an extensive and diverse literature about students with ASD in mainstream schools, there has been scant research that has specifically focused on studying the participation of students with ASD in mainstream schools. As participation is of central interest in this thesis, three key studies (Falkmer et al. 2012; Humphrey & Lewis, 2008a; Saggers et al., 2011) will be reviewed in the first instance, prior to discussion of the broader literature on students with ASD in mainstream schools. Falkmer et al. (2012) studied the perceptions of participation of 22 students with ASD and 382 of their classmates in Sweden using a 46-item questionnaire. They also investigated correlations between what activities the students wanted to participate in and actual participation. The authors

defined participation as “a subjective feeling of belonging to, and being active in, a specific context” (Falkmer et al., 2012, p. 191). Their results indicated that students with ASD perceived that their participation in mainstream school was lower than that of their classmates. They perceived they were more bullied, less liked, less involved in interaction with classmates, less understood by their teachers, and more insecure in the school environment than their classmates. However, on the following items: asking classmates to be allowed to join in with them, answering classmates, being with classmates during recess, talking to classmates in the classroom, students perceived that they were participating to a personally desirable extent. Their results emphasise the importance of eliciting students’ perceptions of participation in school (Falkmer et al., 2012).

In a second key study, Humphrey and Lewis (2008a) used a multiple case-study design to study four mainstream secondary schools in England with the aim of exploring the barriers to learning and participation for students with ASD and the way school practices either facilitated or constrained their participation. The authors defined participation as the quality of learning experience and engagement in activities (Humphrey & Lewis, 2008). Data collection involved interviews with students with ASD, teachers, learning support assistants, Special Education Co-ordinators (SENCOs), senior managers and parents. Classroom and lunchtime observations; analysis of policy documents and individual education plans; and student diaries were also used to gather data. There were four key findings from the study. The ethos of the school and commitment to inclusion influenced the practices in relation to students with ASD. For example, in some schools students were physically placed in mainstream classes but were not experiencing participation. School leaders determined the ethos of the school and influenced the experiences and practices of the teaching staff. Communication, both within the school and beyond to parents was another key factor. Students’ individual needs were more likely to be accommodated when lines of communication were open. Responsibility for students’ learning was another important factor. Although teachers were required to make accommodations for the students with ASD, the level of curriculum differentiation varied within and across schools and the use of learning support assistants in some cases meant that teachers “absolved their responsibility” to adapt the curriculum (Humphrey & Lewis, 2008a, p. 136). Finally, the study revealed particular participation issues related to the unique pattern of difficulties that characterise ASD. For example, students experienced stress due to the unpredictable environment and unplanned changes in secondary school. Sensory issues in noisy classroom environments also acted as a barrier to their participation (Humphrey & Lewis, 2008a). This study highlights the multiple factors at the school and individual student level that can enable or constrain the participation of students with ASD.

A third key study by Saggers et al. (2011) involved interviews with nine secondary school students about their experiences in mainstream schools in Australia. The aim was to identify factors that enabled, or constrained, the learning and participation of students with ASD in mainstream schools. Despite their stated focus on participation the authors did not describe their conceptualisation of participation. Similar to Humphrey and Lewis (2008) their findings revealed multiple factors that students perceived could facilitate and/or constrain their participation including: (a) teacher characteristics, (b) curriculum-related issues, (c) support mechanisms, (d) friendships, (e) environmental considerations, and (d) teasing and bullying (Saggers et al., 2011).

It is evident from these studies that valuable knowledge can be gained from obtaining students perceptions of participation in mainstream school. However, the literature on student participation is under-developed. One aspect that has not been explored in these studies is the perceptions of students with ASD about their influence on participation. In this thesis it is contended that students with ASD are active agents who influence their participation in mainstream school within the constraints and opportunities of school structures. There is a need for further research that includes the perspectives of students with ASD about their participation in mainstream schools (Falkmer et al., 2012) and elicits not only their experiences of participation but also their perceptions about how they have influenced their participation.

There is a much larger body of research that has explored perceptions and experiences of mainstream school from the perspective of parents of children with ASD and/or students with ASD. This literature will now be reviewed to develop a richer understanding of students with ASD in mainstream schools.

2.3 THEMES OF THE BROADER LITERATURE ON STUDENTS WITH ASD IN MAINSTREAM SCHOOL

A prevailing theme in the literature is that students with ASD experience social exclusion in mainstream schools, including isolation, poor friendship quality and bullying. A number of quantitative studies using self-report scales have investigated the social networks of students with ASD compared with their typically developing peers in the United States. The students with ASD who participated in these studies reported significantly poorer friendship quality, lower social network centrality (but not total isolation), lower peer acceptance and less reciprocity in their friendship nominations (Chamberlain et al., 2007; Kasari, Locke, Gulsrud, Rotheram-Fuller, 2011; Locke et al., 2010). They also rated their friendships as lower on the dimensions of closeness and help (Bauminger et al., 2008; Calder et al., 2012). In most studies they reported greater loneliness

(Bauminger & Kasari, 2000; Bauminger et al., 2003; Locke et al., 2010) indicating an awareness of their social challenges (Locke et al., 2010). In contrast, Chamberlain et al. (2007) did not find that students with ASD reported greater loneliness. The authors posed two possible explanations for this contradictory finding: students may have been aware of the unacceptance of their peers, or acceptance might not have been important to them (Chamberlain et al., 2007).

Students with ASD have also been observed to spend more time engaged in solitary behaviour at school than their typically developing peers (Bauminger et al., 2003) and students with special needs (Humphrey & Symes, 2011). Bauminger et al. (2003) conducted observational research in the United States on the peer interaction patterns of students with ASD compared with their typically developing peers. They found that although students with ASD demonstrated a high level of social initiation, they spent only half the time in social interactions with peers compared with their typically developing peers. This suggests that solitude was not freely chosen by these students with ASD.

Qualitative studies eliciting students' perspectives provide a more nuanced insight into their experiences of friendships at school. Although students with ASD have consistently reported difficulties establishing and maintaining friendships with peers in several studies (Connor, 2000; Hay & Winn, 2005; Poon et al., 2012; Saggers et al., 2011), most students also reported having one or a few friends at school (Connor, 2000; Hay & Winn, 2005; Humphrey & Lewis, 2008; Poon et al., 2012; Saggers et al., 2011) and some reported friendships to be a positive aspect of school (Saggers et al., 2011). Furthermore, in two studies in the United Kingdom, students with ASD reported that the social isolation and bullying they experienced was counteracted by support from their friends (Humphrey & Lewis, 2008; Humphrey & Symes, 2010).

Another theme is the bullying experienced by students with ASD in mainstream schools (Batten et al., 2006; Cappadocia et al., 2012; Chen & Schwartz, 2012; Humphrey & Symes, 2010; Reid, 2011; Reid & Batten, 2006; Rowley et al., 2012). High rates of bullying have been reported for students with ASD in both mainstream primary (Chen & Schwartz, 2012) and secondary schools (Humphrey & Symes, 2010; Poon et al., 2012; Reid & Batten, 2006; Rowley et al., 2012). It is also evident that students with ASD experience higher levels of bullying than students with other special needs and typically developing students (Humphrey & Symes, 2010; Jones & Frederickson, 2010; Wainscot et al., 2008) and lower levels of social support (Humphrey & Symes, 2010). Forms of bullying reported in the literature include: peer shunning, teasing, and physical assaults. In two studies bullying was reported to be frequent (Cappadocia et al., 2012; Humphrey & Lewis, 2008) and

prolonged (Cappadocia et al., 2012). For example, Cappadocia et al. (2012) examined the bullying experiences of students with ASD in Canada by surveying 192 parents of children with ASD. They found that 77% of the parents reported that their child had been bullied at school within the last month, and 30% reported victimisation two or more times per week. Furthermore, 54% of parents reported their child had been bullied for a period of more than one year. It has also been reported by students and parents that students are particularly vulnerable to bullying during unstructured times such as breaks and between classes where there is less adult supervision (Batten et al., 2006; Connor, 2000; Whitaker, 2007). Consequently, students have identified the need for access to ‘safe havens’ such as the library during break times (Tobias, 2009).

Literature indicates that bullying at school has resulted in a range of negative impacts for students with ASD. Parents have reported that their children have experienced disruptions to their educational progress, with 62% of the 1362 parents in a study by Batten et al. (2006) reporting that bullying led to their child with ASD missing or changing schools and/or refusing to go to school. Parents have also reported that their children experienced reduced self-esteem and social skills (Batten et al., 2006), mental health difficulties (Batten et al., 2006; Cappadocia et al., 2012; Penney, 2013), and suicidal feelings and self-harming behaviour (Batten et al., 2006). These findings are concerning as quantitative studies of the mental health of young people with ASD indicate that young people with ASD already experience a significantly greater incidence of mental health difficulties than their typically developing peers (Gurney, McPheeters, & Davis, 2006; Hebron & Humphrey, 2012; Kim Szatmari, Bryson, Streiner & Wilson, 2000) and students with other special needs (Hebron & Humphrey, 2012). Furthermore, bullying at school has resulted in ongoing mental health difficulties in adulthood for people with ASD (Aspect, 2012; Portaway & Johnson, 2005; Wittemeyer et al., 2011). In several studies examining the lived experience of adults with ASD, participants have reported that bullying at school has resulted in enduring mental health difficulties such as anxiety, depression and/or obsessive-compulsive behaviours (Aspect, 2012; Portaway & Johnson, 2005; Wittemeyer et al., 2011).

Considering the extent of bullying experienced by students with ASD in mainstream schools, it is perhaps unsurprising that students have often reported that they perceive their differences in a negative light (Humphrey & Lewis, 2008; Poon et al., 2012). Students have also reported that they don’t want to be perceived as different from their peers and thus try to conceal their differences (Carrington & Graham, 2001; Humphrey & Lewis, 2008; Scuitto et al., 2012). For example, in an Australian qualitative study eliciting the perceptions of two students with Asperger’s syndrome about their school experiences (Carrington & Graham, 2001) students reported using

‘masquerading’, which refers to “the normal facade that some individuals with Asperger's Syndrome adopt in order to mask their social differences” (Carrington et al., 2003, p. 19). Similarly, in a study in the United Kingdom by Humphrey and Lewis (2008), the majority of the 20 students interviewed reported having to adapt themselves in order to fit in with their peers, but this compromised their self-concepts. However, a smaller number of students expressed acceptance of their differences (Humphrey & Lewis, 2008). This could suggest that these students may have been less focused on fitting in or did not wish to do so if it meant compromising their self-concepts and highlights the heterogeneity of students with ASD.

It is evident that peers have a significant influence on the social inclusion of students with ASD (Ochs et al., 2001; Symes & Humphrey, 2010). As Ochs et al. state (2001, p. 399) state: “the practice of inclusion rests primarily on unaffected schoolmates rather than teachers, who typically are occupied monitoring academic progress and disciplinary transgressions across a range of children”. The impact of peers can be positive or negative. Ochs et al. (2001) observed 16 students with High Functioning Autism (HFA) in public high schools in the United States and reported that peers supported students with ASD by demonstrating how to complete classroom activities, correcting the student when they behaved inappropriately, giving the student credit for good ideas and by befriending them. They also impeded inclusion by rejecting students and scorning their ‘odd’ behaviours. Ochs et al. (2001, p. 416) observed that students whose diagnosis was not public to the school were “more likely to be neglected by busy classmates and teachers who have not been primed to notice the child’s social withdrawal nor to understand when and how to intervene”. Consequently they concluded that: “positive inclusion experiences appear to be facilitated by peer awareness of the capabilities and impairments of HFA children” (Ochs et al., 2001, p.415). In a study by Reid (2011) in the United Kingdom, students with ASD reported the perception that increased peer understanding would improve their social inclusion. However, in this study a lack of peer understanding of ASD was a current barrier to their social inclusion (Reid, 2011).

It is also evident that the social and communication difficulties of students with ASD are a barrier to their social inclusion (Brewin et al., 2008; Symes & Humphrey, 2010). Parents perceive that their children’s social relationships with peers may be improved through providing social skills training to their children with ASD in mainstream schools (Batten et al., 2006; Brewin et al., 2008). However, in a number of studies parents have reported that social skills training remains a significant gap in provision in mainstream schools (Batten et al., 2006; Reid & Batten, 2006; Rowley et al., 2012). In contrast, quantitative research by Osborne and Reed (2011) identified that

students' social skills improved over a one-year period through their exposure to typically developing peers at school (Osborne & Reed, 2011).

A prevailing theme in the literature is that students with ASD are excluded within and from mainstream schools (Barnard et al., 2000; Batten et al., 2006; IAN, 2010; Lilley, 2012; McDonald, 2010; Osler & Osler, 2002; Reid, 2011; Starr et al., 2006; Stewart, 2012; Watson, 2009). Several forms of exclusion have been reported: being denied enrolment, having reduced hours of attendance, and high rates of suspension and exclusions. In several studies parents of students with ASD have reported encountering principals who used discriminating practices in relation to the enrolment of their children with ASD based on lack of resources and consequently parents had to search to find a mainstream school that would accept their child with ASD (Lilley, 2012; McDonald, 2010; Watson, 2009). In an Australian study, Lilley (2012) interviewed 22 mothers of children with ASD whose children were transitioning to primary school. Ten of these mothers reported efforts by principals to exclude their sons or daughters at the point of primary school entry. Although it is illegal in Australia to outright deny enrolment to students with disabilities under the *Disability Discrimination Act 1992*, some principals appear to have discouraged parents from enrolling their children in their schools. As has been proposed, in these instances, it seems that principals are using the problem of inadequate resources at their school to support inclusion as a reason not to enroll the child (Lilley, 2012; McDonald, 2010). This raises the question as to what extent principals act as inclusion gatekeepers at the point of entry into mainstream schools.

Parents of children with ASD also widely report in the literature that once their children are enrolled in mainstream school they continue to be excluded, both in the form of suspensions and permanent exclusions (Barnard et al., 2000; Batten et al., 2006; IAN, 2010; Osler & Osler, 2002; Reid, 2011; Starr et al., 2006; Stewart, 2012). For example, in a study by Batten et al. (2006) of 1367 parents of children with ASD, one in five of the children with autism were excluded from school. These figures were higher for students with Asperger's syndrome with almost one in four of these children being excluded from school (Batten et al., 2006). Parents reported that exclusions were frequent, 67% of children experienced more than one fixed term exclusion, 16% had been excluded more than ten times and 24% of excluded children were excluded permanently. Exclusions have led to students missing large portions of school (Barnard et al., 2000; Batten et al., 2006; Stewart, 2012). Batten et al. (2006, p. 25) reported that of the children who had been excluded "34% had missed a term or more of school and 10% had missed more than a whole school year, over the last two years alone". These large periods out of school are likely to have had negative implications for their academic participation and achievement.

Informal exclusions have also been widely reported by parents of children with ASD in the literature (Barnard et al., 2000; Batten et al., 2006; Jones et al., 2007; Lilley, 2012; McDonald, 2010; Starr & Foy, 2010; Stewart, 2012). These involve schools restricting students' hours of attendance so that students attend school for only part of the day. Parents have reported in several studies that these practices happen frequently (Barnard et al., 2000; Batten et al., 2006; Stewart, 2012). For example, in Stewart's (2012) study in Northern Ireland 14% of 151 parents reported that informal exclusions happened more than three times. Almost 10% reported that their child had missed between half a term and one school year and a further 5% reported that their child had missed more than one year of school. In a number of studies parents have reported a range of negative outcomes for their children as a result of their exclusion including lowered self-esteem, feelings of isolation and depression, and disrupted academic progress (Barnard et al., 2002; Batten et al., 2006; Connor, 2000; Osler & Osler, 2002).

Exclusions are perceived by parents to represent inappropriate behaviour management by schools as they fail to recognise the contribution of students' disability to their behavioural difficulties (IAN, 2010; Starr et al., 2006; Whitaker, 2007). For instance, in a survey by Whitaker (2007) in the United Kingdom of the perceptions of 172 parents about educational provision in mainstream schools for students with ASD parents reported that some school staff had been reluctant to accept that ASD-related characteristics may have contributed to students' challenging behaviours and instead employed management strategies focused on punishment.

A prominent theme in the literature is that students with ASD have special learning needs that need to be identified early by mainstream schools and appropriately accommodated (Batten et al., 2006; Penney, 2013; Reid, 2011; Stewart, 2012). The few studies that have captured students' perceptions of their academic participation in mainstream schools reveal academic challenges. In a study by Connor (2000) of 16 students with ASD spanning year seven to eleven in the United Kingdom, the students reported difficulties with certain subjects such as music, maths and english and a dislike for certain subjects which often stemmed from their dislike of the teacher of that subject. In an Australian study by Saggers et al. (2011) of nine secondary school students with ASD, students reported difficulties with handwriting and the academic workload. Similarly, in a study by Poon et al. (2012) of four secondary school students with ASD attending mainstream schools in Singapore, some students reported experiencing stress as a result of the academic workload. Finally, in a recent Australian study by Autism Spectrum Australia (2013) the majority of 100 adolescents with ASD surveyed reported that their educational needs were not being met and perceived that they needed more support with class work, homework and assessment.

Although parents perceive that their children have special learning needs that need to be identified early by mainstream schools, in most studies parents report a lack of timely learning support from schools for children's special learning needs (Batten et al., 2006; Reid, 2011; Renty & Roeyers, 2006; Stewart, 2012; Tissot & Evans, 2006). In Stewart's (2012) study, 52% of the 151 parents reported that their child had to wait over a year for educational supports, 22% waited over two years and one in ten children waited more than three years. Furthermore, in several of these studies parents perceived that the lack of timely support led to a range of negative outcomes for their children (Batten et al., 2006; Reid, 2011; Stewart, 2012; Tissot & Evans, 2006). For example, over 80% of the 151 parents in the study by Stewart (2012) reported that it had harmed their children's social and communication skills, 71% reported that their children's educational progress had been harmed, 70% said their children's behavior had been effected, 65% said it had harmed their children's mental health and over 45% said it had affected their children's physical health.

Another common theme is a lack of ongoing curriculum adjustments for students with ASD (Batten et al., 2006; Parsons & Lewis, 2010; Penney, 2013; Reid, 2011; Stewart, 2012; Tissot & Evans, 2006). Although most children with ASD eventually obtain a document outlining the adjustments needed to support their learning needs in mainstream schools (for example a statement of learning needs in the United Kingdom) in many studies parents have reported that these adjustments were not made (Batten et al., 2006; Parsons & Lewis, 2010; Penney, 2013; Reid, 2011; Stewart, 2012; Tissot & Evans, 2006). This reflects a failure on the part of schools to uphold their legal obligations to make 'reasonable adjustments' to enable the participation of students at school. Parents perceived that the lack of adjustments meant their children's educational needs were not met, resulting in poor educational progress (Reid, 2011; Stewart, 2012) and failure to perform to their educational potential (Starr et al., 2001). One study reported contrasting results. Parsons et al. (2009) surveyed parents of children with ASD about their views and experiences of educational provision. Most of the 66 parents surveyed reported that the school was doing well to help their child and they were making good academic progress. It could be that this study captured parent perceptions at a point in time when their child was experiencing inclusive provision. The authors themselves noted that some parents had been unsatisfied with previous educational provision (Parsons et al., 2009). This could suggest that experiences changed over time for these students. This indicates a need for future research to develop an understanding of student participation over time.

Although students with ASD have heterogeneous learning styles (Tsantis, 2004) and academic abilities (Griswold, Barnhill, Smith Myles, Hagiwara & Simpson, 2002), they share ASD-related characteristics to varying degrees. These include executive functioning problems and sensory

processing difficulties that can impact on their academic participation schools (Ashburner et al., 2008; Jarhomi, Bryce & Swanson, 2013; Zingerevich & LaVesser, 2008).

Executive functioning problems include difficulties changing cognitive set when completing challenging tasks (Ozonoff & McEvoy, 1994; Ozonoff, Pennington, & Rogers, 1991; Prior & Hoffman, 1990), difficulties with forward planning (Ozonoff et al., 1991) and self-regulatory impairments (Jarhomi et al., 2013). These difficulties have been found to impact on students' academic engagement (Jahromi et al., 2013) and participation at school (Zingerevich & LaVesser, 2008). Zingerevich & LaVesser (2008) studied the contribution of executive functions to participation in school activities of 24 children diagnosed with ASD aged six to nine years in the United States. They found "the abilities to resist impulsive responses, to stop a behavior at the appropriate time, and to regulate emotional responses contributed to successful participation of children diagnosed with high functioning ASD in school activities" (Zingerevich & LaVesser, 2008, p. 436).

Zingerevich & LaVesser (2008) also reported a positive relationship between sensory processing scores and school participation scores – that is the children with the most typical sensory processing had higher participation scores. Ashburner et al. (2008) conducted a study in Australia that compared 28 children with ASD (with average-range IQ) with 51 age and gender matched typically developing peers on their sensory processing and educational outcomes. They found that auditory filtering difficulties were significantly negatively associated with academic performance and attention to cognitive tasks and contributed significantly to the academic underachievement of students with ASD (Ashburner et al., 2008). As students with ASD can be hypersensitive to visual and auditory stimuli and have difficulty filtering these stimuli out, environmental factors within school classrooms such as background noise and fluorescent lighting can impact their participation (Ashburner et al., 2008; Hay & Winn, 2005). Students in numerous studies have reported that environmental factors such as noise and lighting can lead to increased anxiety and difficulties with concentration and this can have negative implications for their behaviour and academic participation (Batten et al., 2006; Hay & Winn, 2005; Humphrey & Lewis, 2008a; Penney, 2013; Reid, 2011; Saggers et al., 2011). In several studies parents have also commented on the impact of sensory issues on their children's participation at school when the physical environment was not adapted (Batten et al., 2006; Penney, 2013; Reid, 2011; Stewart, 2012). For example, in a Canadian study by Penney (2013) of nine parents of students with ASD the parents reported that sensory issues put their children at risk for academic problems, increased anxiety, behavioral difficulties, and school refusal and dropout. Notably, in a number of the studies parents reported that schools

failed to make the necessary accommodations to classroom environments to support their children's sensory needs resulting in reduced participation (Batten et al., 2006; Penney, 2013; Reid, 2011; Stewart, 2012).

The findings of several studies indicate that when accommodations to the physical environment are made, student participation at school can improve (Humphrey & Lewis, 2008; Mostafa, 2008). Humphrey and Lewis (2008a) found that simple adaptations to the physical environment appeared to help reduce student anxiety and facilitate learning. For instance, one school in their study placed students with ASD in the quiet, well-behaved class and designated areas such as the library as a place that could be used to "escape the chaos of the corridor" (Humphrey & Lewis, 2008a, p. 38). Furthermore, Mostafa (2008) conducted a study in Egypt on the impact of architectural design on the attention span and behaviour of 12 students with ASD and found that students taught in modified classroom environments with improved acoustic and spatial organisation responded faster and with improved attention and behaviour. Taken together, these studies indicate that there are certain ASD-related characteristics that impact on academic participation and that the physical environment can either exacerbate these difficulties, or minimise them when adaptations are made.

A further theme in the literature is that school staff such as principals, teachers and teacher aides can either facilitate or constrain the participation of students with ASD (Humphrey & Lewis, 2008; McDonald, 2010; Penney, 2013; Reid, 2011). In several studies, parents of students with ASD have reported a perception that principals can positively or negatively influence the inclusion of their children (Humphrey & Lewis, 2008; McDonald, 2010; Penney, 2013; Reid, 2011), and that effective school leadership improved their children's experiences of participation (Humphrey & Lewis, 2008; Penney, 2013). For example, in a Canadian study by Penney (2013) parents of children with ASD and co-occurring anxiety and/or depression discussed how effective leadership improved their children's experiences at school. They reported that leadership staff encouraged an overall culture of acceptance and helped enforce learning and behavioral modifications.

Parents and students with ASD perceive that having teachers who understand ASD is crucial to the inclusion of students with ASD (Penney, 2013; Renty & Roeyers, 2006; Saggers et al., 2011; Scuitto et al., 2012; Tobias, 2009). In several studies, parents have reported that when teachers understand and accommodate ASD and its unique manifestation in each child, this improves student inclusion at school (Brewin et al., 2008; Reid, 2011; Scuitto et al., 2012; Tobias, 2009). For instance, in a qualitative survey involving 27 adults with Asperger Syndrome and 59 parents of children with ASD in the United States, participants reported that teachers who were open to

difference, and who showed genuine concern, respect and flexibility in their approach had a positive impact on the school experience of students with ASD (Scuitto et al., 2012). In an Australian study by Saggers et al. (2011) students also reported that their participation was enhanced when their teachers understood, accepted and encouraged student differences and took an interest in individual students. However, both parents and students overwhelmingly reported that a lack of knowledge of ASD by teachers was a current barrier to the inclusion of students, and indicated the need for more ASD-specific teacher training (Barnard et al., 2000; Batten et al., 2006; Brewin et al., 2008; Jindal-Snape et al., 2005; Reid, 2011; Starr et al., 2001; Starr et al., 2006; Stewart, 2012; Waddington & Reed, 2006).

Teacher aides have also been found to both facilitate and constrain the participation of students with ASD (Humphrey & Lewis, 2008; Osborne & Reed, 2011; Saggers et al., 2011). In studies incorporating the perspectives of students with ASD it appears that teacher aide support is experienced as a double-edged sword – students reported that teacher aides assisted them to remain on task during lessons, but also marked them as different from their peers when they wished to blend in (Hay & Winn, 2005; Humphrey & Lewis, 2008; Saggers et al., 2011). Similarly, Osborne and Reed (2011) found that while teacher aide presence helped reduce some emotional and behavioural problems, it also impeded students' social behaviour.

It is evident from the review thus far that students with ASD experience social isolation, bullying, exclusion and academic challenges in mainstream schools due to ASD-related characteristics, features of the social, academic and physical environment and the interactions between student and environment. Although extensive literature has been reviewed in this section, much of this literature has used quantitative methods, particularly questionnaires to obtain parent perspectives. Although quantitative methods are effective for understanding the breadth of an issue, such as the number of students with ASD that are excluded from mainstream schools, they do not provide an in-depth understanding of students experiences of participation. Relatively few studies have used qualitative methods to examine the lived experience of students with ASD in mainstream schools (Carrington & Graham, 2001; Connor, 2000; Humphrey & Lewis, 2008b; Penney, 2013; Saggers et al., 2011). Even fewer have examined their perceptions and lived experience specifically in relation to their participation in mainstream school (Humphrey & Lewis, 2008; Saggers et al., 2011). This indicates a need for further qualitative research that elicits students' perceptions and lived experiences of participation in mainstream.

The limited extant research on the participation of students with ASD in mainstream schools has captured student perceptions and experiences of participation at one point in time (See Falkmer et al., 2012; Humphrey & Lewis, 2008; Saggers et al., 2011). A central proposition of this thesis is that participation is dynamic and changeable and a more complete empirical picture of this is best achieved by seeking an understanding of participation across the schooling years. Consequently, the next section of the review explores the current state of knowledge about the participation of students with ASD in mainstream schools over time.

2.4 PARTICIPATION IN MAINSTREAM SCHOOL OVER TIME

To date there is minimal research that has sought to gain a longer-term view of participation across the schooling years in mainstream school of students with ASD from the perspective of students with ASD and their parents. Three studies were identified that have examined the mainstream education of students with disability over time (Hanson et al., 2001; O'Connor, 2012; Wendelborg & Tossebro, 2010). Two of these were longitudinal investigations that focused on the concept of educational participation (Wendelborg & Tossebro, 2010) and the inclusion in mainstream education over time for students with disabilities as a general group (Hanson et al., 2001). The third study examined the educational journeys of students with Behavioural, Emotional and Social Difficulties (BESD) using retrospective interviews and life grids (O'Connor, 2012). Although the focus of these studies was not students with ASD, nevertheless they provide insight into the complexities of and changes in participation over time.

Studies that have examined the participation of students with disabilities over time have demonstrated that their educational placements become less ‘inclusive’ as students progress through the years (Hanson et al., 2001; Wendelborg & Tossebro, 2010). Hanson et al. (2001) explored the educational placement pathways of 25 students with disabilities, including five with ASD, over a five-year period in the primary school years in the United States. They conducted repeat semi-structured interviews with the students’ parents and found that as the children moved through the years less of them were in ‘full inclusion’ placements (fulltime in a mainstream classroom), with half remaining for the full five years. Parents perceived there was a combination of influences on children’s placements. They reported discrepancies between their children’s performance and behaviour and classroom demands as they progressed in schooling. The level of support at the school also influenced whether or not the child could be accommodated, as did child characteristics. For example, children with behavioural difficulties were not considered “good candidates” for inclusive environments (Hanson et al., 2001, p. 77). Similar findings in relation to behaviour and

placement decisions have been reported in relation to children with ASD. Yianni-Coudurier et al. (2008) examined the link between the characteristics of children with ASD and their weekly hours of mainstream classroom inclusion in a sample of 77 children aged three to five years in France and found that the children with more ‘aberrant behaviours’ had fewer hours of attendance in mainstream classrooms.

Wendelborg and Tossebro (2010) analysed data from a larger, longitudinal life course study of classroom participation of primary school children with disabilities attending mainstream school in Norway. Data were collected from 26 parents via interviews and surveys at three intervals between 1998 and 2006 (with 603, 490 and 443 participating respectively). To measure classroom participation, parents were asked to rate the proportion of school time the child spent in the regular class/group during the school day. The results revealed a reduction in children’s participation in the regular classroom over the course of primary school, and an increase in the number of hours of special education (Wendelborg & Tossebro, 2010). Twenty-six parents were also interviewed and described feeling more marginalised from their children’s education over time, with reduced cooperation from the classroom teacher. This indicates a link between the experiences of the children and their parents. Similar to the findings of Hanson et al. (2001) the authors reported that the gap between the children’s characteristics (such as the severity of their disability) and the demands of their school environment increased from early to late primary school and the children were unable to keep up relative to their peers (Wendelborg & Tossebro, 2010). One could argue that this may be likely to continue in secondary school, since expectations on young people continue to increase based on age-graded assumptions about ‘normal’ developmental trajectories. For example, in secondary school young people are expected to display increased competence and independence (Pearce & Forlin, 2005; Shaddock, 2005). The gap between these expectations and students skills may be particularly pronounced for students with ASD as they make fewer gains in adaptive behaviour over time compared with their typically developing peers and those with other forms of disability (Baghdadli et al., 2012). Research that develops an understanding of the educational trajectories of students with ASD is needed in order to understand their participation over primary and secondary school.

Although these studies appear to offer insight into participation and inclusion over time for students with disabilities generally, their measurement of participation/inclusion (e.g. hours of attendance in a mainstream classroom) is simplistic. It fails to acknowledge that students can be present in a mainstream classroom and not actually participating. Participation involves actively taking part in the social and academic activities of the classroom and feeling a sense of belonging (Booth &

Ainscow, 2003). Therefore these studies actually measure changes in placements over time. However, the data they obtained through qualitative interviews provided insight into the child and school factors that interact to influence participation. This indicates the value of using qualitative methods to obtain perceptions of participation in future research.

O'Connor (2012) studied the educational journeys of secondary school students with BESD in the United Kingdom from the perspectives of ten teachers, ten parents and ten students aged 14 to 16 using interviews. She reported that most of the students experienced disrupted attendance, and all but one had been excluded from mainstream school at least once. Following their exclusion they experienced two pathways: they were either placed in special school or in alternative provision. Therefore, like the findings of Hanson et al. (2001) and Wendelborg and Tossebro (2010) students' placements became more restrictive over time. By using qualitative methods O'Connor (2012) was able to provide in-depth case studies of the students' educational pathways and explored the factors perceived to have led to student exclusion. For example, she found that teachers adopted a "utilitarian approach" to students with BESD and employed a variety of strategies to remove the students from the system (O'Connor, 2012, p. 186). Given the value of qualitative methods that incorporate students and parents' perspectives in providing insights into student educational pathways over time, similar methods can be applied to explore the participation of students with ASD over time from the perspective of students with ASD and their parents.

One study has provided a broad description of the characteristics of children with ASD over time, but did not have a particular focus on participation in education. Despite this, it provides some understanding of how children with ASD change over time. Church, Alisanski and Amanullah (2000) examined the general academic, social and behaviour characteristics of 40 children with ASD between the ages of three and 15 years in the United States using retrospective chart review. They reported that although children's social abilities improved by secondary school, at this time they became aware of their differences and experienced sadness, anxiety and rejection. Social skills remained the greatest challenge for these children in their secondary school years. Furthermore, over the time period studied the number of students enrolled in general education decreased which parallels the findings for students with disabilities generally (see Hanson et al., 2001; Wendelborg & Tossebro, 2010).

Taken together, these studies suggest that attendance in mainstream classrooms decreases over time for students with disabilities, including those with ASD. They also suggest that placement over time is influenced by a combination of child characteristics and school factors and the interactions

between these factors. There is a need for future research to study the participation of students with ASD in mainstream school, taking account of participation across the years of schooling and for such research to acknowledge the complexity of participation in its conceptualisation and design, rather than simply measuring placement change over time.

There is one previous study that indirectly offers insight into participation over time for students with ASD (McDonald, 2010). McDonald (2010) conducted a qualitative study in Western Australia focused on how parents of children with ASD deal with their children's education over time. The sample was comprised of in-depth case studies of six families and data were collected via repeat, semi-structured interviews, participant observation, informal interviews and documentary data sources. Parents reported that their children did not experience 'reliable inclusion' in mainstream schools over the course of their schooling, had many changes of school and some eventually left mainstream school to participate in home schooling (McDonald, 2010). The other children eventually found "educational fit" in a mainstream environment. "Educational fit" was defined as an appropriate education that "maximizes their progress and increases their independence and skill levels in all areas" (McDonald, 2010, p. 8). There were a number of features in these environments that enabled "educational fit" including: (a) a welcoming school culture, (b) a supportive Education Support Unit, (c) staff who were devoted and committed to the development of the child and who were self-aware about their expertise, (d) student-centred decision making, (e) the presence of a key member on staff to promote evidence-based inclusive practice, and (f) equal and trusting partnerships between parents and staff (McDonald, 2010, p. 181). McDonald (2010) noted:

Such elements ensured that irrespective of difficulties faced, parents and staff could work as a team to creatively solve problems as they arose. This ensured that the maximum educational progress was achieved by the child with an ASD and the 'inclusive' expertise of the staff was continually improving. (p. 181)

Although this study indirectly offers insight into the participation of students with ASD over time, it did not include student perceptions and experiences of participation, which may differ from their parents. Further research is needed from the perspective of both students and parents is therefore warranted.

This section of the literature review has provided an overview of the participation of students with disability in mainstream schools over time and has highlighted the paucity of research specifically exploring the participation of students with ASD over time. It also highlights how parental and student experiences interface and the importance of gaining both parent and student perspectives in

order to gain a comprehensive understanding of the participation dynamic. Therefore the final section of this review will explore previous research investigating parent perceptions and experiences of supporting their children's education in mainstream school.

2.5 PARENT PERCEPTIONS AND EXPERIENCES OF SUPPORTING THEIR CHILDREN'S MAINSTREAM EDUCATION

There have been a large number of studies which have elicited parent perspectives about the mainstream education of their children with ASD (Barnard et al., 2000; Batten et al., 2006; Benson et al., 2008; Brewin et al., 2008; Lilley, 2012; McDonald, 2010; Parsons et al., 2009; Penney, 2013; Reid, 2011; Renty & Roeyers, 2006; Scuitto et al., 2012; Stewart, 2012; Stoner et al., 2005; Stoner & Angell, 2006; Tissot & Evans, 2006; Tobias, 2009; Whitaker, 2007). The majority of these studies focus on parent perceptions of satisfaction with educational provision rather than on their lived experiences of supporting their children's participation (Barnard et al., 2000; Batten et al., 2006; Brewin et al., 2008; Reid, 2011; Renty & Roeyers, 2006; Stewart, 2012; Whitaker, 2007). Despite this, they have still captured some information about parents' experience of their role in their children's education and their findings in relation to this are reviewed in this section.

A central theme reported in the parent literature is parents' 'fight' for educational provision (Barnard et al., 2000; Batten et al., 2006; McDonald, 2010; Penney, 2013; Reid, 2011; Stoner et al., 2005; Tissot & Evans, 2006). For example, Tissot and Evans (2006) surveyed 738 parents in the United Kingdom about their perceptions of securing educational provision for their children with ASD. Parents reported that initially securing special needs provision in mainstream school for their children with ASD was a stressful process requiring persistence on their part and prolonged negotiation with educational providers. They described feeling distressed by the length of time it took to secure provision (Tissot & Evans, 2006). After initially securing this provision, parents reported that they had to continually advocate for adjustments to be made for their children and this often resulted in conflictual relationships with educational professionals (Tissot & Evans, 2006). In several other studies parents of children with ASD have reported engaging in a continuous 'fight' that required vigilance on their part (Batten et al., 2006; McDonald, 2010; Penney, 2013; Reid, 2011; Stewart, 2012). In studies in the United Kingdom (Batten et al., 2006; Reid, 2011) and Northern Ireland (Stewart, 2012) parents have also reported appealing to the Special Educational Needs and Disability Tribunal in order to have adjustments implemented at their children's schools.

These findings suggest that parents face significant challenges in negotiating with schools for learning supports for their children in these schools. However, there is a caveat on the interpretation

of these findings. Many of these surveys obtained their sample of parents through the National Autistic Society in the United Kingdom (see Batten et al., 2006; Reid, 2011; Stewart, 2012) and as Parsons et al. (2009) and Whitaker (2007) have previously acknowledged parents may have joined this organisation due to difficulties with their children's mainstream educational provision and therefore may report more negative experiences and greater dissatisfaction with mainstream schools.

Another prominent theme in the literature is the importance of home-school communication for parental involvement in their children's mainstream education (Benson et al., 2008; McDonald, 2010; Stoner et al., 2005; Stoner & Angell, 2006) and for the successful inclusion of their children with ASD in mainstream education (Humphrey & Lewis, 2008a, McDonald, 2010; Waddington & Reed, 2006). For example, Benson et al. (2008) studied the factors that influence the extent to which mothers of children with ASD were involved in their children's mainstream education. Questionnaire and interview data were collected from mothers and teachers of 95 children with ASD attending public schools in the United States. Benson et al. (2008) found that school facilitation through meetings and phone calls with mothers was the most important predictor of maternal school involvement. Although parents have consistently acknowledged the importance of communication between home and school in a number of studies (Batten et al., 2006; McDonald, 2010; Waddington & Reed, 2006; Whitaker, 2007), in some studies, parents have also reported that schools failed to keep them informed (Batten et al., 2006; McDonald, 2010; Whitaker, 2007). This suggests that much like their children with ASD, parents can be excluded from participation in their children's mainstream education.

The final major theme is the impact of children's experiences at school on parents' lives. In a number of studies parents have reported they were frequently called into school to support their child or to pick them up when they were excluded from activities for periods of the day (Barnard et al., 2002; Batten et al., 2006; Starr & Foy, 2010; Stewart, 2012). Parents have also reported a reduced ability to work or giving up employment entirely (Batten et al., 2006; Brewin et al., 2008; McDonald, 2010; Penney, 2013; Reid, 2011), which resulted in a decreased family income (Batten et al., 2006; McDonald, 2010). In a large number of international and Australian studies parents also report either choosing or feeling forced to home school their children due to mainstream schools' inability and/or unwillingness to provide inclusive educational provision for their children (Batten et al., 2006; Hurlbutt, 2011; Kidd & Kaczmarek, 2010; McDonald, 2010; McDonald & Lopes, 2012; Parsons & Lewis, 2010; Reid, 2011). For example, Hurlbutt (2011) interviewed 10 parents of children with ASD who were home schooling their children with ASD in the United

States about their perceptions and experiences of home schooling. The overarching theme of the results was that parents perceived that through home schooling they had found an educational approach that worked for their child and that schools had been either unwilling and/or unable to provide an effective education (Hurlbutt, 2011). These findings illustrate that the lives of children with ASD and their parents are linked and thus students' experiences of education shape their parents experiences.

There have been relatively few in-depth qualitative studies focused specifically on parental perceptions and experiences of supporting their children's education in mainstream school (Lilley, 2012; McDonald, 2010; Stoner et al., 2005). However, the few that have been conducted provide further insight into the nature of parents' involvement in the education of their children with ASD and the impacts on parents' lives. Stoner et al. (2005) studied parent perceptions of interactions with education professionals in a sample of eight parents of children with ASD in the United States using semi-structured interviews. They found that parents expected their children's schools to make accommodations to support their participation and when this did not transpire, it resulted in a reduction of trust between the parents and teacher and parents became more vigilant in their efforts to make certain that their children had access to an education that met their unique needs (Stoner et al., 2005). Moreover, they reported "negative experiences reduced trust to such an extent that parents reported not trusting education professionals, even when their individual situations had improved" (Stoner et al., 2005, p. 46).

In a subsequent paper Stoner and Angell (2006) reported on parent perceptions of role engagement based on the data from their earlier study (Stoner et al., 2005). They found that parents performed four different roles: negotiator, monitor, supporter and advocate. They noted: "the degree of perceived parental trust in education professionals affected the extent of their engagement in the roles" (Stoner & Angell, 2006, p. 177). For example, when parents reported low trust, engagement in the roles of negotiator and monitor increased. In contrast, when they had more trust, parents relaxed their engagement in these roles and increased their role of supporter (Stoner & Angell, 2006).

As mentioned in the previous section of this review, McDonald (2010) conducted a qualitative study in Western Australia with six parents focused on how parents of children with ASD deal with their children's education over time. McDonald (2010) developed a substantive theory reporting that parents engaged in a process of "seeking progressive fit" for their children. There were four iterative stages in this process:

- (1) Beginning battle – the stage where parents struggle to find an appropriate diagnosis.
- (2) Waging war – the stage where parents fight to seek, gain, maintain and create educational fit.
- (3) Strategising solutions – the stage where parents strategise solutions to remedy the constant difficulties associated with education.
- (4) Framing futures – the stage where parents frame futures and begin redressing life imbalance. (McDonald & Lopes, 2012, p. 8)

McDonald (2010, p. 194) also found that parents own life circumstances sometimes interfered with their ability to advocate which resulted in them advocating in a “waxing and waning” manner. There were also a range of negative impacts on parents’ lives including: (a) physical and mental health problems, (b) marital strain or breakdown, and (c) reduced ability to work or giving up employment entirely (McDonald, 2010).

Finally, Lilley (2012) conducted a longitudinal study in Australia of the experiences of 22 mothers whose children with ASD were transitioning into primary school. Her results indicated that 10 of the 22 mothers perceived that their children experienced stigma upon entry into mainstream school and these mothers experienced “attachment stigma” as a result which refers to a “particularly intense dynamic of stigma wherein mothers feel that the slights directed against their son and daughter are insults to their selves” (Lilley, 2013, p. 9). This finding adds weight to the proposition in this thesis that children’s educational experiences impact on their parents’ lives.

Taken together, these qualitative studies demonstrate that valuable insight can be gained from exploring parents’ perceptions and lived experiences of supporting their children’s education in mainstream schools. They also provide further evidence that the lives of children with ASD and their parents are linked and thus students’ experiences at school shape their parents’ experiences and vice versa. There is a need for further research incorporating parents’ perceptions and experiences (McDonald, 2010), with a particular focus on how they have supported their children’s participation in mainstream school. The extant studies focused solely on parents’ perceptions and experiences and did not incorporate the perspective of students. It is widely acknowledged that there is a need for more research incorporating the student perspective on mainstream schooling experiences (Connor, 2000; Carrington & Graham, 2001; Falkmer et al., 2012; Humphrey & Lewis, 2008; Humphrey & Parkinson, 2006; Osler & Osler, 2002; Poon et al., 2012). This highlights the

need for future research to investigate parents' and students' perceptions and experiences of participation and how these interface.

2.6 CHAPTER SUMMARY

In summary, students with ASD experience social isolation, bullying, exclusion and academic challenges in mainstream schools due to ASD-related characteristics, features of the social, academic and physical environment and the interactions between student and environment.

Although the literature on students with ASD in mainstream schools is extensive, relatively few studies have examined the lived experience of students with ASD in mainstream schools

(Carrington & Graham, 2001; Connor, 2000; Humphrey & Lewis, 2008b; Penney, 2013; Saggers et al., 2011) and even less have specifically examined the lived experience of students with ASD in relation to their participation in mainstream school (Humphrey & Lewis, 2008; Saggers et al., 2011).

There has been a tendency for research to focus on student perceptions and experiences of participation at one point in time. A central proposition of this thesis is that participation changes over time and there is a need to understand the participation of students with ASD in mainstream school across the years. Additionally, this review has revealed that there have been relatively few in-depth qualitative studies focused specifically on parental perceptions and experiences of supporting their children's education in mainstream school (Lilley, 2012; McDonald, 2010; Stoner et al., 2005). However, the few that exist indicate that the perceptions and experiences of children with ASD and their parents are linked and students' experiences of education shape their parents experiences and vice versa.

Overall, it is evident from the review that further qualitative research is required from the perspectives of students with ASD and their parents with a focus on exploring how they perceive, experience and respond to their participation across the schooling years. As such, Life Course Theory (Elder & Giele, 2009) offers an appropriate conceptual approach to guide a study seeking to explore in more depth parent and student experiences of participation in mainstream schools. In the next chapter, the basic assumptions of this theory are discussed and applied to the issue of participation in mainstream school for students with ASD.

CHAPTER THREE: CONCEPTUAL FRAMEWORK

Based on the literature review it is evident that there is a paucity of research on the participation of students with ASD in mainstream school and which captures a longer-term view of participation across the school years. The conceptual framework, which takes account of this empirical and conceptual gap is presented in this chapter.

Life Course Theory guides this study on the perspectives of students with ASD and their parents about participation of students with ASD in mainstream school across time. Specifically, the variant of Life Course Theory developed by Elder (1994; 1998) and described by Elder & Giele (2009) is discussed. This chapter begins with a discussion of the theory and its previous research applications with the purpose of developing a rationale for its use in this thesis. This is followed by a discussion of the central tenets of the theory as they apply to this study to conceptualise participation in mainstream school over time.

3.1 RATIONALE FOR LIFE COURSE THEORY

As background to applying Life Course Theory as an approach for conceptualising participation over time the major critiques of the theory are explored. It has been suggested that this theory does not have a coherent theoretical base (Dewindle, 2003; Mayer, 2009). Furthermore, it is used by individual disciplines but is not often applied in an interdisciplinary manner (Alwin, 2012). This has led to a lack of shared definitions of the core concepts of Life Course Theory (Alwin, 2012) and to the development of different theoretical strands. This study identifies with the particular strand of Life Course Theory known as the ‘traditional approach’ (Dewindle, 2003) developed by Elder (1994). It emphasises time, context and process as salient influences on human development (Elder, 1994; 1998) and highlights the need for research to explicitly consider individuals’ and families’ lives over time and in their historical and multiple social contexts (Elder & Giele, 2009).

Some life course researchers have noted that research application of Life Course Theory can produce descriptive rather than explanatory research results (Dewindle, 2003; Mayer, 2009). Since it was established in the literature review that very little is known about the participation of students with ASD in mainstream school over time, it was deemed appropriate to use a theory that provides concepts to explore participation but is not prescriptive about the relationships between concepts. Furthermore, it is not the intention in this study to explain participation, but to understand

perceptions and experiences of it from the perspectives of students with ASD and their parents. Therefore the value of its application in this study is that it provides this study with a “conceptual toolkit” (Mayer, 2009, p. 423) of orienting concepts to understand participation over time.

3.1.1 Previous research applications of Life Course Theory

Life Course Theory incorporates ideas from a range of disciplines including anthropology, demography, economics, sociology, and developmental psychology (Bengston & Allen, 2009). Life course researchers utilise both quantitative and qualitative data collection methods (Giele & Elder, 1998). Quantitative methods include longitudinal survey and panel designs (Mayer, 2009) and qualitative methods include retrospective life story interviews (Elder & Giele, 2009). Life Course Theory has been applied in research within a diverse range of fields and topics including: health (Chen, Martin & Matthews, 2006; Elstad, 2005; Kaplan, Baltrus & Raghunathan, 2007; Kim & Durden, 2007); education (Farnes, 1996; Gorard, Rees, Fevre & Furlong, 1998; Gorard, Rees, Fevre & Welland, 2001; Janosz, Archambault, Morizot & Pagani, 2008; McLeod & Fettes, 2007; Pallas, 2002; Wendelborg & Tossebro, 2010); transition to adulthood (Robette, 2010; Salmela-Aro, Kiuru, Nurmi & Eerola, 2011; Shannahan, 2000); criminal offending trajectories (Carlsson, 2012; Laub & Sampson, 2003); social exclusion (Dewindle, 2003; Edwards & Mackenzie, 2005); ageing (Kuh & New Dynamics of Ageing Preparatory Network, 2007) and stress (Gotlib & Wheaton, 1997).

Of particular relevance to this study is the application of the theory in investigations of children and young people’s engagement, achievement and participation in schooling over time (see Janosz et al., 2008; McLeod & Fettes, 2007; Wendelborg & Tossebro, 2010). Janosz et al. (2008) explored the school engagement trajectories of 13,300 typically developing teenagers aged 12-16 years and their predictive relationship to dropout using data obtained from the New Approaches New Solutions (NANS) longitudinal data set (2002– 2005). By employing growth mixture modeling they derived seven trajectory types: normative, stable-high, stable-moderate, transitory increasing, transitory decreasing, decreasing, and increasing. They discovered that students who displayed a rapid decrease in engagement or who reported low levels of engagement at the start of adolescence had increased likelihood of drop out (Janosz et al., 2008).

McLeod and Fettes (2007) sought to understand the association between children’s mental health problems and educational attainment. Using data from the Children of the National Longitudinal Surveys of Youth data set and growth mixture modeling the authors identified trajectories of internalising and externalising problems from childhood through adolescence. They found that

young people who had high levels of mental health problems in either childhood or adolescence had poorer eventual educational attainment than other young people. To explain these trajectories they assessed three mediators of educational attainment: academic aptitude, disruptive behaviors, and educational expectations. They concluded that “educational expectations are important mediators independent of academic aptitude and disruptive behaviors [and] social responses to youths’ mental health problems contribute importantly to their disrupted educational trajectories” (McLeod & Fettes, 2007, p. 653).

What is common to these two studies was their use of longitudinal datasets and quantitative data analysis to identify trajectory classes and to explore the factors mediating student engagement over time. This was possible in these cases as these researchers had access to large, longitudinal datasets and there was a substantive body of literature from which to formulate hypotheses about the mediating factors of engagement, which could then be tested in the research. In Australia there is currently no national data on students with disability in mainstream schools (Department of Education, 2014), which impedes the conduct of large-scale, longitudinal studies on the participation of students with disabilities or specifically, students with ASD. Furthermore, since little is known about the participation of students with ASD over time an exploratory qualitative approach underpinned by Life Course Theory is appropriate.

There is one study that has used Life Course Theory and data obtained from a longitudinal life course study ‘growing up with disabilities’ in Norway to understand the participation of students with disabilities over time (Wendelborg & Tossebro, 2010). As described in the literature review this study uncovered a pattern of decreased participation over time for students with disabilities. The authors attributed this to the growing gap between student abilities and the school environment as the students progressed into late primary school. As previously noted, the study measured participation based on children’s hours of attendance, but this approach fails to acknowledge that students can be present in a classroom and not actually participating. Therefore, they really captured a pattern of decreased attendance in mainstream environments. This suggests the need for this research to acknowledge the complexity of participation in conceptualisation and design. In this study participation is defined as actively taking part in the social and academic activities of the classroom and feeling a sense of belonging (Booth & Ainscow, 2003).

In general, these studies demonstrate how the application of Life Course Theory enables understanding of changes in engagement and participation in school over time and identification of

influences on engagement and participation. Given the participation challenges of students with ASD in mainstream schools that have been uncovered through cross-sectional designs in previous research, there is a need for this research to understand their participation over time. The focus of this research is students with ASD and their parents' perceptions and experiences of participation in mainstream school and through these the aim is to elucidate an understanding of participation trajectories over time and what characterises experiences across the school years.

3.2 CENTRAL ASSUMPTIONS OF LIFE COURSE THEORY

The concept of 'life course' is defined as "a sequence of socially defined events and roles that the individual enacts over time" (Giele & Elder, 1998, p. 22). Life Course Theory posits that human development is a lifelong process and therefore cannot be understood from one point in time - it must be understood as a process over time (Kok, 2005). This can be achieved through either longitudinal design or retrospective research designs using quantitative or qualitative methods (Giele & Elder, 1998). In chapter two the literature review established the need in this study for qualitative research from the perspective of students with ASD and their parents to understand the complexities and dynamics of participation of students with ASD in mainstream school and across the school years.

3.2.1 Trajectories and transitions

The idea of trajectories and transitions across the life course is central to Life Course Theory. In this case, the life course consists of multiple, intersecting trajectories such as education, work and family. A trajectory refers to a sequence of life events, transitions and changes in roles (Sakmann & Wingens, 2003). Transitions are embedded in trajectories (Elder, 1994) and are defined as "the socially defined changeover between two positions in a particular domain of life" (Dewindle, 2003, p. 118). They give trajectories "specific form and meaning" by indicating when a trajectory commenced and finished and how long it lasted (Macmillan & Elliason, 2003, p. 531). For example, in relation to educational trajectories, the transition to school marks the beginning of the trajectory, and the transition from secondary school to work would mark the end of the trajectory.

There is research to indicate that particular transitions in mainstream school are difficult for students with ASD (Dillon & Underwood, 2012; Dixon & Tanner 2013; Maras & Aveling, 2006). In this thesis, it is assumed that these will influence their participation at these points. Two significant transitions within students' educational trajectories identified from the literature are the

transition to school and transition to secondary school and as evidenced by several studies, these reinforce the potential participation issues for students with ASD.

Walker et al. (2012) collected parent and teacher perceptions from 53 participants on the transition to school for students with developmental disabilities in Queensland, Australia. They reported both benefits and challenges to their participation. Benefits for students included: opportunities for socialisation with peers, academic learning and improvements in language and communication. Challenges included: schools frequently contacting parents regarding their child's behaviour, lack of supervision, the school being unprepared for the child and/or failing to accommodate the child's needs (Walker et al., 2012). Encouragingly, most parents and teachers reported that overall there were more benefits than challenges. However, some children were perceived to have experienced a problematic transition due to difficulties organising themselves, working independently, persisting with classroom tasks and maintaining attention. The authors offer two explanations for this finding: the children were inadequately prepared prior to school entry and/or there was a mismatch between children's skills and teacher's expectations and classroom resources (Walker et al., 2012).

The transition to secondary school is characterised by multiple changes including: an increased school size; more complex social environment; larger and more diverse student population; increased expectations about behaviour and achievement; increased homework; increased number of school subjects and different teachers for each subject. All of this coincides with physical changes, which are occurring with the onset of puberty (Adreon & Stella, 2001). This transition is known to be challenging for all students, but is likely to be a particularly challenging for students with ASD due to their difficulties coping with change (Maras & Aveling, 2006). In two studies secondary schools students with ASD have reported finding the complex environment in secondary school to be particularly stressful (Hay & Winn, 2005; Humphrey & Lewis, 2008). Several studies have explored the perspectives of parents of children with ASD who are transitioning to high school (Dillon & Underwood, 2012; Dixon & Tanner 2013; Maras & Aveling, 2006). In Dillon and Underwood's (2012) qualitative study of fifteen parents of children with ASD in the United Kingdom some parents reported their children's transition was problematic in the first year due to (a) lack of home-school communication, (b) lack of teacher understanding of ASD, (c) an inflexible approach to support, and (d) features of the physical environment which caused sensory issues. Strategies that reportedly helped transition were an individualised and child-centred approach and ongoing home-school communication (Dillon & Underwood, 2012).

Dixon and Tanner (2013) conducted case study research on two students with Asperger's syndrome in New South Wales, Australia, incorporating parent and student perspectives. Participants reported that transition support for academic work was minimal leading to academic challenges. Parents acknowledged the importance of transition preparation, ongoing collaboration between home and school and the need to involve students in the transition process to facilitate successful transition.

Finally, Maras and Aveling (2006) explored the perspectives of six students with ASD and six of their parents of students in the United Kingdom on the transition to secondary school. Students reported that the increased workload and homework were significant stressors. Organisational and orientation issues were also noted such as navigating larger school campuses; taking books home and organising materials for each subject. What helped make it a successful transition for some students was: (a) repeated visits to the new school prior to commencing, (b) provision of a safe haven to "cool off", (c) having the same learning support assistant also provided some continuity to students, and (d) adjustments to their timetables (Maras & Aveling, 2006).

These studies suggest that the participation of students with ASD can change during these key transition periods depending on the responses of the school. When schools are prepared for and accommodate the student with ASD they may experience good participation in that environment. However, if schools do not make accommodations student participation may decrease. In this thesis, part of forming a comprehensive understanding of student participation over time will necessitate exploring perceptions of participation during transitions and perceptions of the school responses.

3.2.2 Turning points

Trajectories are not predetermined, they can be altered through turning points and within a trajectory there can be multiple turning points (Wheaton & Gotlib, 1997). A turning point involves a lasting shift (either positive or negative) in the direction of a life course trajectory (Wheaton & Gotlib, 1997). In relation to schooling, a turning point for a student with ASD could be moving from a special school into a mainstream school if the student then participated in a full academic curriculum, obtained a high school certificate and went on to attend university. Rutter (1996, p. 614) identified three categories of life events that can be characterised as turning points: (a) those that either close or open up opportunities; (b) those that produce a lasting change to a person's views or expectations of others, and (c) those that produce a lasting change in the environment. Furthermore, the same life event can be a turning point for one individual, but not for another depending on how they are interpreted by each individual (Hutchison, 2005).

The concept of turning points has been used effectively in qualitative studies within the field of criminology to understand processes of change in offending (see Carlsson, 2012). Carlsson (2012, p. 12) notes that they “help us explore, analyse and understand these life course processes in (greater) depth”. While scant empirical knowledge exists about participation of students with ASD in mainstream school across the years as a whole, it is proposed herein that their participation will change over time as result of the dynamic interplay between the student and school environment. The concept of turning points can thus be used in this study to understand changes in their participation over time. In this thesis, parent perceptions of turning points in their children’s participation over time will be explored.

3.2.3 Timing

The developmental consequences of events and transitions are conditional on their timing in a person’s life (Elder, Kirkpatrick Johnson & Crosnoe, 2003). Therefore, “the same events or experiences may affect individuals in different ways depending on when they occur in the life course” (Elder et al., 2003, p. 12). Life Course Theory considers four forms of time which interact over the life span: *individual* time (chronological age); *social* time which refers to “the incidence, duration, and sequence of roles, and to relevant expectations and beliefs based on age” (Elder, 1994, p. 6); *generational* time (the cohort in which people are grouped), and *historical* time (societal or large-scale changes or events) (Kok, 2007).

The two forms of time relevant in this study to understanding participation are individual time and social time. In the literature review previous life course research on participation over time for students with disabilities indicated that as students increased in age (individual time) their development did not keep pace with the age-graded social expectations (social time) in schools and this led to a reduction in their participation in mainstream classes over time (Wendelborg & Tossebro, 2010). Research on the transitions of students with ASD suggests this may occur for them too, for example Walker et al. (2012) suggested some children had difficulty transitioning into year one because their competencies did not match with teacher’s expectations. In this thesis, the intention is to understand the participation of students with ASD in mainstream school over time from the perspectives of parents. Parents perceptions of student participation at key transitions such as the transition to secondary school will be explored which may identify interactions between their individual time and social time. Student perceptions of their current participation will be explored and it is acknowledged that their perceptions will be shaped by their age and their expectations of what they should be participating in at that age (social timing).

3.2.4 Linked lives

In the literature review it was revealed that the lives of students with ASD and their parents are linked. For example, when schools did not provide appropriate modifications to the curriculum and environment to enable the inclusion of students with ASD some mothers made the decision to remove their child from the system and therefore gave up their employment in order to home school their child (Batten et al., 2006; McDonald 2010). This then led to reduced income for the family (Batten et al., 2006; Brewin et al., 2008). Student experiences were also shown to lead to changes in other life course trajectories such as health changes, relationship changes. This resonates the notion lives being lived interdependently with contextual influences “expressed through a network of shared relationships” (Elder, 1998, p. 4). This means that: “one person’s resources, resource deficits, successes, failures, chronic strains, and (expected or unexpected) transitions can become focal conditions, even turning points, in the lives of others, especially other family members” (Moen & Hernandez, 2009, p. 259)

In this thesis, it is argued that students’ participation experiences will interact with their parents’ life course and shape how parents perceive and experience the participation of their children. As a result, it is important to also explore how parents perceive their children’s experiences of participation have impacted their own life course trajectories in relation to employment, health and relationships.

3.2.5 Human agency

Life course theory posits that individuals “construct their own life course through the choices and actions they take within the opportunities and constraints of history and structural circumstances” (Elder, 1998, p. 4). It was demonstrated in the literature review that people within the mainstream school environment such as school principals, teachers, teacher aides and peers all have the capacity to constrain or facilitate the participation of students with ASD in mainstream schools. However, it was also evident that parents have varying capacity to shape their children’s participation through the actions they take. For example, by advocating for changes to school environments, parents’ actions may shape and/or improve their children’s participation. Therefore, parents’ perceptions of the influence of these broader contextual elements on their children’s participation across the school years is also of interest in this thesis.

From a conceptual approach, this directs attention in this thesis to the interplay of structure and agency in understanding the participation of students with ASD. Structure and agency are

interlinked therefore studying agency also involves studying structure as Settersen and Gannon (2005, p. 38) state: “people have the ability to change structures (that is, that the relationship between people and structures is reciprocal) and that both social structures and human lives and the connection between them, are dynamic”. Consistent with this, it is proposed that students with ASD have the capacity to influence their participation within the constraints and opportunities of social structure. This research will explore the perspectives of students about how they have influenced their participation in mainstream school and how school environments constrained or facilitated their expressions of agency.

As noted above, parents’ expressions of agency include advocating for accommodations to be made in mainstream schools in order for their children to participate (Tissot & Evans, 2009). Therefore in this study it is proposed that the participation of students with ASD will be influenced by their parents’ expressions of agency within the constraints and opportunities of social structure. This research will explore parents’ perceptions of their involvement in the education of their children over time with a particular focus on exploring the strategies used to influence their children’s participation. It will also explore parents’ perceptions about the extent to which their efforts exerted an influence over schools practices in relation to the participation of their children.

The nature and balance of agency and structure may change within individuals as they move through different periods of life or enter different environments (Hitlin & Elder, 2007). For example, in the case of students with ASD, transition to a different school environment is likely to present a different opportunity structure. This indicates the need to understand both parent and student perceptions and experiences of participation in context and the barriers, facilitators and actions this dynamic generated.

3.2.6 Cumulative processes

Elder (1998, p. 7) purports that “early events can have lasting consequences; by affecting subsequent transitions” and set in motion “cumulating advantages and disadvantages”. According to O’Rand (2009, p. 123) the main consequence of this is “the emergence, persistence, and widening or narrowing of inequality in different aspects of wellbeing-social, economic, physical, and psychological”. Prior research suggests that there are negative consequences in adulthood for people with ASD who experienced poor participation in school. Research with adults with ASD has demonstrated a range of poor adult outcomes including: low rates of employment (compared with rates for the general population) (Australian Bureau of Statistics [ABS], 2009; Barnard et al., 2000; Portaway & Johnson, 2005; Wittemeyer et al., 2011); low rates of post-school qualification (ABS,

2009); prolonged dependency on parents and mental health difficulties (Aspect, 2012; Portaway & Johnson, 2005; Wittemeyer et al., 2011).

Some life course researchers suggest that children's early experiences of school are of particular significance in shaping their educational trajectories. Rentwistle, Alexander and Olson (2003) studied the achievement trajectories of typically developing children in primary school and found that students' achievement remained stable over the course of primary school, the students with the highest scores in grade one, had the highest in grade seven. Consequently, they noted that early experiences at school are "critically important for children's future development because it marks the start of a life trajectory that encompasses both schooling and work careers" (Rentwistle et al., 2003, p. 229). Additionally, Gorard et al. (1998) assert that since it is a child's first experience of formal learning "their experience of success or failure might help create a long-term learner identity for them" (Gorard et al., 1998, p. 408) and if they experience an early sense of failure this can negatively influence their later attitudes towards learning (Gorard et al., 2001). In this thesis, it is proposed to capture the participation trajectories of students with ASD and explore cumulative processes by investigating parents' perceptions of their children's early experiences of participation in education and how these experiences were perceived to have impacted their children's subsequent participation.

Although life course researchers tend to emphasise the importance of early life events for future life, past research indicates that cumulative processes can be either path-dependent (e.g. the inequality continues over time) or reversible (O'Rand, 2009). O'Rand (2009, p. 134) purports that path-dependence is influenced by: (a) the timing of relative advantage or disadvantage, (b) the sequential contingency of statuses with age, and (c) duration of exposure over the life span to advantaged or disadvantaged conditions. Reversibility of cumulative processes is fostered by: (a) life course events, (b) experience in pivotal institutions such as school, and (c) general changes in life conditions which can all bring "either significant adversity or opportunity" (O'Rand 2009, p. 135). This study therefore acknowledges that cumulative processes may influence student participation across the schooling years and that initial experiences of participation are likely to be important, but may remain stable over time, or change over time dependent upon contextual influences.

3.3 CHAPTER SUMMARY

This chapter has outlined the conceptual framework for understanding participation in mainstream school over time. It has demonstrated how concepts from Life Course Theory (Elder & Giele, 2009)

direct this thesis to understand participation as a process over time and to explore particular influences on participation over time. A number of concepts were discussed that frame the understanding of participation over time: trajectories and transitions, turning points, timing, human agency, linked lives and cumulative processes. The concept of timing suggests that students will interpret their participation based on their age and the social expectations attached to their age. Human agency points to the need to understand that both students' participation and their parents' participation are the result of a combination of their efforts to influence school environments within the opportunities and constraints of those environments. Furthermore, the balance of agency and structure may change for individuals over time. For example, if they transition into different school environments that have different opportunity structures. Linked lives suggests lives are interdependent therefore students' participation experiences will influence their parents life course experiences and conversely, the actions taken by parents will influence their children's participation. Cumulative processes may influence student participation over time and initial experiences of participation may either remain stable over time or change over time. The next chapter details the qualitative methodology used to carry out the study.

CHAPTER FOUR: METHODOLOGY

In this chapter, the qualitative methodology which is underpinned by an interpretivist paradigm and framed by Life Course Theory (Elder & Giele, 2009) is presented. The rationale for employing a qualitative approach was twofold. Firstly, as indicated in the literature review, there has been limited research to date that has captured a rich empirical picture of participation of students with ASD in mainstream school across the schooling years from the perspective of students and parents and thus little is known about this topic. This lack of a detailed understanding of the topic, therefore necessitates exploratory qualitative research as a basis for developing more targeted research. Furthermore, in this study participation is conceptualised as a complex process and qualitative research is recognised to be particularly useful in research that aims to interpret and understand complex processes (Creswell, 2007).

This chapter is divided into three sections. The first section provides an overview of the qualitative research design including the aims and research questions and methods. The second section describes the stages of the study from sampling and recruitment through to the dissemination of the findings. In the final section ethical issues are discussed.

4.1 RESEARCH DESIGN

4.1.1 Research aims and questions

The primary aim of the study was to understand the participation of students with ASD in mainstream school over time through the perspective and experiences of parents and students. The study also aimed to understand the participation trajectories of students with ASD and parents' experiences of supporting their children's participation in mainstream school across the schooling years. The research questions framing this inquiry were:

1. How do parents perceive and make sense of their children's participation in mainstream school over time?
2. What are the participation trajectories of students with ASD attending mainstream schools?
3. What are parents' experiences of supporting their children's participation in mainstream school over time?
4. How do students currently experience participation in mainstream schools?

4.1.2 Overview of the research design

A qualitative approach was employed in this study. Within the broad field of qualitative research there are diverse ontological and epistemological perspectives and methods (Patton, 2002; Schwandt, 2000). This study is underpinned by an interpretivist paradigm. Interpretivist research is based on the premise that human social action is inherently meaningful and people construct their own subjective meanings of their social worlds (Schwandt, 2000). Interpretivists posit that it is possible to understand these meanings and it is the role of the researcher to make sense of them (Schwandt, 2000). Since this study focuses on understanding the perceptions and experiences of students with ASD and their parents regarding participation in mainstream school over time an interpretivist paradigm was appropriate.

Within an interpretivist paradigm there are a number of theoretical orientations (Schwandt, 2000). This study is informed by phenomenology. There are different strands of phenomenology, though broadly they share the aim of gaining a deep understanding of the nature of peoples' everyday lived experiences and how they make sense of these experiences (Patton, 2002). Traditional phenomenological studies seek to uncover the meaning, structure and essence of the lived experience of a phenomenon (Patton, 2002). However, according to Patton (2002, p. 107) "one can employ a phenomenological perspective to elucidate the importance of using methods that capture people's experiences of the world without conducting a phenomenological study that focuses on the essence of shared experience". Therefore this study employs a phenomenological perspective to understand the perceptions and lived experiences of students with ASD and their parents of participation in mainstream school over time.

The use of a phenomenological perspective in this study directed attention to methods that thoroughly capture how students and parents perceive, experience and make sense of participation. Semi-structured interviews were the chosen method in this research. They enabled a detailed investigation of the perspectives of students and parents and in-depth understanding of their subjective experiences and personal contexts (Ritchie, 2003). Furthermore, they are considered useful when discussing sensitive topics or when complex issues and processes need to be explored (Legard, Keegan & Ward, 2003), as was the case in this study. Both parents and students were interviewed separately as it was acknowledged that they experience and interpret the same events differently and both perspectives are valid. The parent data were the primary sources used to understand student participation in mainstream school over time. The intention with the student

perspective was to capture a snapshot of their current participation experiences in mainstream school.

A repeat interview design was chosen to obtain the parent perspective and experience as it was acknowledged that a single interview might not elicit sufficiently detailed information, and the implicit meaning of their lived experience (Charmaz, 1999). Therefore, two semi-structured interviews were conducted with each parent two months apart. The first interview focused on obtaining their perspective on their children's participation overall in mainstream school taking account of the participation from commencement of schooling to current time. This allowed a description of participation trajectories to be developed through the analysis. In this case, a retrospective perspective was taken due to the constraints of time and resources associated with the PhD study.

A trajectory grid was developed for each student based on the information from the first parent interview (see Appendix 12 for an example). This approach was adapted from life grids, which are a visual method for plotting life events over time (Wilson, Cunningham-Burley, Bancroft, Backett-Milburn & Masters, 2007). Life grids have been successfully employed in previous quantitative and qualitative life course research to capture retrospective data (Blane, 1996; O'Connor, 2012; Parry, Thomson & Fowkes, 1999; Wilson et al., 2007). The trajectories comprised a grid structure with one axis representing the passage of time from when the student was born until present. On the other axis there were a number of columns that represented different aspects of the student's lives. The columns were: the individual child context, family context, social context, school context, historical context, level and quality of school participation and parent involvement. Events were then plotted onto the grids under the relevant time period and column. These trajectory grids were then presented to parents in a second interview conducted two months later. The second interview provided opportunity for clarification, to explore the themes of participation in more detail and parents' experiences of supporting their children's participation over the time of schooling relevant to each individual child. A detailed description of each interview guide is provided later in the chapter.

A single, semi-structured interview design was chosen to elicit the student perspective. This design has been used previously to obtain the perspectives of young people with ASD (Carrington & Graham, 2001; Poon et al., 2012). It was considered sufficient in this study to obtain a snapshot of their current experiences of mainstream school. Furthermore, prior to completing the fieldwork it was anticipated that it could be challenging to engage the students in an interview and obtain in-depth information about their

experiences as literature indicated that during research interviews young people with ASD had experienced difficulty communicating and provided brief responses (See Preece, 2002; Preece & Jordan, 2010). The perceived benefit of the single interview design was that it would place less relational demands on the students compared with the extended contact required in a repeat interview design as was used with the parents (Vincent, 2012). However, the limitations of the single interview design must also be acknowledged. The single interview did not enable exploration of how student perceptions may have changed over time. Multiple interviews would have enabled exploration of this and would have created an opportunity to explore their experiences in greater depth. A thematic analysis of the parent and student data was undertaken in order to understand their perspectives and experiences of participation in mainstream school over time. The framework for thematic analysis developed by Braun and Clarke (2006) was employed. This framework was deemed appropriate as it provided a systematic structure for the thematic analysis to ensure rigour and has been used previously in qualitative studies on the educational experiences of students with ASD (Hebron & Humphrey, 2012; Humphrey & Symes, 2010). The student and parent data were treated separately during data analysis. The intention was not to use two perspectives to triangulate the information but rather to provide two equally legitimate perceptions of the participation of students with ASD in mainstream school over time. Therefore separate themes for parents and students were developed and are presented in separate results chapters.

4.2 STAGES OF THE STUDY

This section describes how the study was conducted. It describes the stages of the study from sampling and recruitment through to the dissemination of the findings.

4.2.1 Sample

The study took place in Brisbane, Queensland, Australia. Purposive sampling was employed to identify participants. Purpose sampling is useful when a study requires participants with particular characteristics (Lewis, 2003). Inclusion criteria for the research sample were:

- Parents of children with ASD whose children are aged between 12- 18 years and who are currently or have previously attended a mainstream school.
- One student with ASD aged 12-18 years from each parent recruited.
- Reside in South-East Queensland within a 100km radius of Brisbane.

Parents of secondary school aged children with ASD were recruited so that they could participate in interviews about their children's participation in mainstream school and provide a retrospective

perspective of participation across the schooling years. Parents of children who were currently or have previously attended a mainstream school were recruited since literature indicated that enrolments of children with ASD change over time with some being home-schooled following unsuccessful participation in mainstream school (McDonald, 2010). Keeping this sample criterion broad produced a wider sampling frame of parents compared with just sampling parents whose children were currently attending a mainstream school. As the study aimed to explore both the parent and student perspective it was necessary to recruit both parents and students. Parents and students were recruited from within the same families (Table 4.3) for two reasons: because it was anticipated that it may be difficult to obtain a sufficient sample of students as they were considered a hard to reach research population; and because parents could provide the candidate with information about their children's experience of participation, and their social and communication difficulties which would assist the candidate to facilitate enhanced participation of the students in their interviews. The geographical area for recruitment was limited to locations up to 100km from the Brisbane Central Business District (CBD). This was a pragmatic decision due to the limited financial resources to conduct the research. Diversity along the dimensions of gender, type of school and geographical location was sought in the sample to enable exploration of varying experiences of mainstream school.

4.2.2 Recruitment

Parents and students were recruited with the assistance of AQ. This organisation was deemed the most appropriate to identify parents of children with ASD and students with ASD as it is an ASD-specific organisation which provides programs to parents of children with ASD and education and therapy programs to their school-aged children. Gatekeeper approval was obtained from AQ (Appendix 2). The purpose of the study and the expectations of potential participants were discussed with the staff of the organisation and they identified potential participants and sent them the participant information sheets. The research was also advertised on the AQ website for a period of six months. Once parents received the information sheets or saw the information online they contacted the candidate directly if they wanted to find out more information about the research. The organisation was not told the identity of the participants who subsequently engaged in the research. One parent and student were recruited outside of this process. In this case the parent came across an information sheet about the research at a local support group for parents of children with Asperger's syndrome and contacted the candidate directly to express her and her sons desire to participate. As they both met the inclusion criteria they were included in the sample.

4.2.3 Informed consent¹

All parent and student participants were provided with a participant information sheet, which described the study and the implications of their participation in it (Appendix 3 & 4). Parents completed a written consent form prior to their participation in the interviews (Appendix 5). As the students were all under 18 years of age, their parents were required to provide written consent, however it was acknowledged that the students should also have the opportunity to be involved in decisions about whether or not they wanted to be involved in the research (Coyne, 2009); therefore their assent was also obtained. Consequently, a number of strategies were used to inform the students about the research and the implications of their participation in a way that they could understand and give their assent. Since the students all had different capabilities, it was important to ensure that information about the research was presented in a way that would be suitable to each young person. A consent form was developed which used clear, concrete language to explain the purpose of the research; the potential risks; data collection procedures; and the expectations of them as participants (Appendix 6). For those students that required it, a social story™ (Gray, 1994) which provided information about what would happen during their interview such as who the researcher was, what the student would be asked about and how long the interview would last was also read to them (Appendix 7). Understandings about the purpose of the research were exchanged in an interactive process in which the student's understanding was checked by asking what he/she thought the research was about, before explaining the purpose of the research. The students were also given the opportunity to ask questions about the research.

In conducting research interviews with students with ASD there is the potential for acquiescence (Preece & Jordan, 2010). They may feel obliged to say yes, either due to the power imbalance between them and the adult researcher, or because their parents have already given consent for their participation (Beresford, 1997). Therefore, there is a need to look beyond initial agreement for further indicators of consent (Beresford, Tozer, Raibee & Sloper, 2004; Preece & Jordan, 2010). Preece and Jordan (2010) suggest a secondary indicator of consent is the perceived level of engagement that the student displays towards the researcher during their initial meeting. In the first meeting with the students to discuss the research most appeared relaxed and interested in participating. Furthermore, their parents commented that their children were looking forward to having one on one time with the candidate to share their experiences. One student refused to speak during the initial visit and hid under her bed. Although her parent had given consent, it was clear

¹ This section (4.2.3) presents content previously published by Harrington, Foster, Rodger & Ashburner, 2013).

that the student did not want to engage with the candidate. Therefore the interview with this student was cancelled.

Consent is not a one-off agreement; rather it is a continuous process of negotiation (Ramcharan, 2006). The students were informed that they may decline to comment or answer particular questions during their interviews. They were also informed that they had the right to withdraw from the research at any time without giving a reason and without negative consequence. Young people with ASD may not feel confident to withdraw their consent verbally and therefore it may be necessary to look for non-verbal signals (Beresford et al., 2004). Students were offered a ‘stop card’ that they could hand to the candidate if they wished to terminate their interview and were not able to explain this verbally. However, all of the students completed their interviews with none electing to use the ‘stop card’.

4.2.4 Participants

The sample included 11 parents - two males and nine females. Originally nine parents were recruited; however two additional parents (the partners of two of the original nine parents) expressed a desire to also participate and thus were included in the final sample. Parents resided within 100km of the Brisbane CBD. Parents were all of Caucasian ethnicity. Their level of education, occupation and employment status varied (Table 4.1). The sample also included eight students with ASD. Originally nine students were recruited; however one young person withdrew from the research after indicating that she did not wish to participate in an interview. Her parents’ data remained in the study with their permission. The students were aged between twelve and fifteen years, seven were male and one was female. They had two types of ASD diagnoses made by paediatricians: three were diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS); five were diagnosed with Asperger’s syndrome (Table 4.2). They were all able to communicate verbally; however one young person used noticeably less verbal communication than the others and his responses were limited to several words. They attended a range of school environments: three attended state schools, one attended an independent school, one attended a catholic school, one attended special school and two were currently home-schooled. Their enrolments also varied from full-time through to a split placement (school part-time and an ASD-specific placement part-time). The students’ school year levels ranged from year eight through to year eleven. Since the focus of the study was mainstream school experiences, those that were no longer attending a mainstream school were asked to reflect on their retrospective experiences of it.

Table 4.1: Parent participant characteristics

Pseudonym	Age	Gender	Ethnicity	Marital status	Education	Occupation	Employment status
Anna	44	F	Caucasian	Divorced	Bachelor Degree	Retail (online)	Part-time
Sue	50	F	Caucasian	Married	Year 10	Respite carer	Part-time
Sarah	35	F	Caucasian	Married	Diploma	School chaplain	On leave from part-time position
Philip	59	M	Caucasian	Married	Post Graduate	Teacher	Unemployed (Disability Pension)
Hannah	45	F	Caucasian	Married	Unknown	Dietetic assistant	Full-time
Laura	37	F	Caucasian	Divorced & remarried	Year 10	Retail	Part-time
Julia	40	F	Caucasian	Divorced	Year 12	Unknown	Unemployed
Mary	42	F	Caucasian	Married	Year 12	Personal trainer	Part-time
Glen	50	M	Caucasian	Married	Year 12	I.T consultant	Full-time
Jemma	50	F	Caucasian	Married	Year 10	Administration	Part-time
Hayley	48	F	Caucasian	Married	Year 12	Guidance counselor	Part-time

Table 4.2: Student participant characteristics

Pseudonym	Age	Gender	Ethnicity	Diagnosis	School year	Education placement	Enrolment
Paul	14	M	Caucasian	Asperger's syndrome	10	Special school	Part-time
				Epilepsy		*Left school altogether	
				Intellectual Impairment			
Rhys	15	M	Caucasian	PDD-NOS	9	State school	State school part-time & Autism Queensland part-time
Beth	13	F	Caucasian	Asperger's syndrome	8	Home school	Full-time
Luke	13	M	Caucasian	Asperger's syndrome	9	State school	State school part-time & Autism Queensland part-time
Jake	15	M	Caucasian	PDD-NOS	9	Home school *Enrolled in a TAFE program	Home schooled part-time & Autism Queensland part-time
Brendan	13	M	Caucasian	PDD-NOS	8	State school	State school part-time & Autism Queensland part-time
Brad	12	M	Caucasian	Asperger's syndrome	8	Catholic school	Full-time
Declan	15	M	Caucasian	Asperger's syndrome	11	Independent school *Changed to a state school	Full-time

PDD-NOS = Pervasive Developmental Disorder Not Otherwise Specified. TAFE = Technical and Further Education.

School placements reflect participant circumstances at the time of recruitment. Three students had a change of placement during the data collection process as indicated by a *.

Table 4.3: Relationships between parent and student participants

Parent 1	Parent 2	Child (student)
Anna	-	Paul
Sue	-	Rhys
Sarah	-	Beth
Philip	Hannah	Claire
Laura	-	Luke
Julia	-	Jake
Mary	Glen	Brendan
Jemma	-	Brad
Hayley	-	Declan

4.2.5 Development of the interview guides

Separate interview guides were developed for use with parents and students. The semi-structured interview guide used with parents in their first interview was developed on the basis of qualitative research guides (Patton, 2002; Ritchie & Lewis, 2003), the literature, and the concepts of interest in Life Course Theory. The initial parent interview guide was piloted with one parent of a young person with ASD before formal fieldwork commenced. The purpose of piloting was to allow the candidate to trial the questions, see how the sequence of questions worked and develop skills in employing the guide. The pilot participant provided useful feedback about the content and the process of the interview. For example, the participant suggested that summary questions be included at the end of each interview to provide parents with an opportunity to raise any topics that may not have already been covered during the interview. This feedback was incorporated into interview guide to improve it. The pilot data are not reported in the results.

The final parent interview guide was divided into four sections. The first section explored the family context and the parent's perceptions of their children's experiences prior to school. The second section asked parents about their perceptions of their child's experiences in primary school. The third section focused on their perceptions of secondary school. The final section involved

summary questions intended to obtain their overall impression of their children's participation in schooling so far (Appendix 8). The second parent interview guide was developed during fieldwork and as a result of reflections on the first interview. It will be discussed later in the chapter in the section on parent interviews.

The student interview guide was developed on the basis of qualitative research guides (Patton, 2002; Ritchie & Lewis, 2003), concepts from Life Course Theory and through review of the empirical literature on ASD. For instance, several research papers highlighted that children with ASD have difficulty recalling and narrating personally experienced events (Brown, Morris, Nida & Baker-Ward, 2012; Bruck, London, Landa & Goodman, 2007; Millward, Powell, Messer & Jordan, 2000). This supported the need to focus interview questions predominantly on present experiences. Research also indicated that children with ASD may provide limited information in response to open-ended questions (Bruck et al., 2007) and may cope better with simple, closed questions (Preece, 2002). The interview guide was designed to include many closed, yes/no questions and fewer open-ended questions. Furthermore, research suggested that while children with ASD can express basic emotions, they might have difficulty identifying and discussing complex emotions and processes involving the self (Losh & Capps, 2006). Therefore, questions requiring reflection on basic emotions such as sad and happy were included in the guide. The student interview guide was not piloted. It was acknowledged that students with ASD are heterogeneous and thus piloting the method with one student would have little value in terms of learning about potential methodological challenges.

The student interview guide was structured into three sections. The first section asked about their participation before school, the second asked about participation during school and the third asked about their participation after school and on weekends (Appendix 10). This provided the students with a temporal structure that was easy to follow. The interview guide included topics such as teachers, principals, peers, what they liked and didn't like about school, what they participated in at school, what they didn't get to participate in and whether or not they felt they fitted in at school and why.

4.2.6 Preparation for the student interviews

Researchers in the ASD field have indicated that students with ASD may need to be supported to participate in their interviews, particularly through communication strategies (Beresford et al., 2004; Preece, 2002; Preece & Jordan, 2010). Therefore, the candidate undertook significant

preparation prior to conducting the student interviews. Experts in the field were consulted in order to gain insight into practice approaches that could be used to maximise the participation of the students in their interviews. In this case, the candidate's background as a social worker in the ASD field provided professional networks with speech therapists, occupational therapists and teachers and opportunities to understand their approaches to communicating with young people with ASD. Use of a Social Story™ (Gray, 1994) to prepare students for the interview, visual supports, including Picture Communication Symbols™ (PCM), a visual interview schedule and break cards to support student participation in the interviews were key suggestions.

Carol Gray (1994) developed Social Stories™ as a way to share social information with clients with autism to improve their understanding of events and their associated social expectations. Social Stories™ (Gray, 1994) have been successfully transferred to research settings and for example, can be used to prepare people with ASD for a researcher's visit. A Social Story™ used by Beresford et al. (2004) in their research with children with ASD was adapted for this study (Appendix 7). It provided information about what would happen during their interview such as who the researcher was, what the student would be asked about and how long the interview would last.

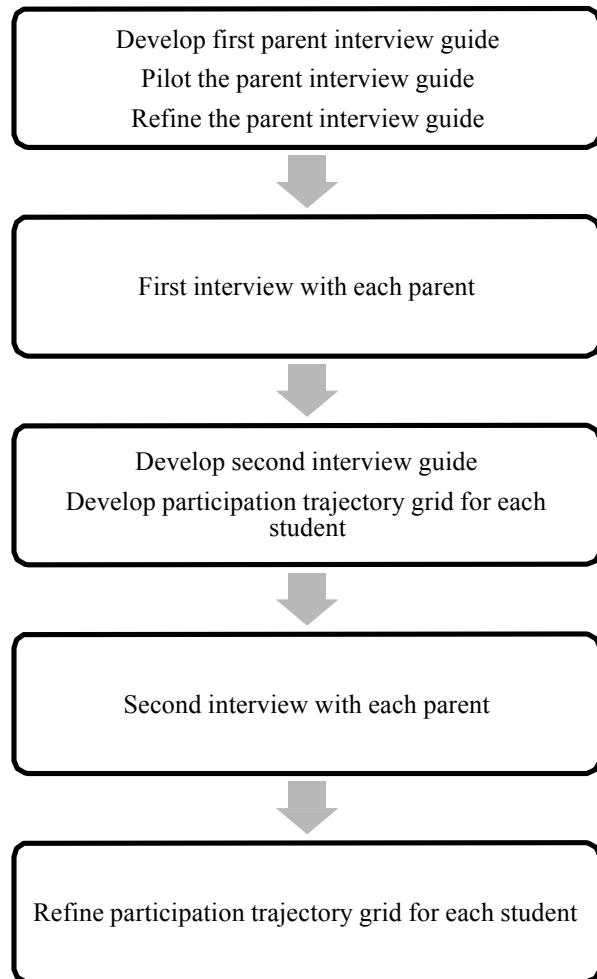
Visuals are often used effectively with people with ASD in clinical contexts to supplement written information and improve language processing (Dettmer, Simpson, Smith Myles & Ganz, 2000; Quill, 1997) and have been successfully used in research (Preece, 2002). In this study a written schedule, which incorporated pictures, was developed for the interviews to indicate the sequence of events that would take place in the interview (Appendix 11). A number of PCM representing different emotions were also obtained. The intention was to present them to the students during interviews if it appeared they required assistance identifying and communicating their feelings. A 'break card' (featuring a symbol of a young person taking a break) and a 'stop card' (featuring a stop symbol) were also obtained. Students could hand these to the candidate if they wished to have a break or to terminate their interview.

Prior to the student interviews, parents were also consulted about their child's particular social and communication abilities and how best to support these. The candidate also took the time to build rapport with students so that their anxiety was minimised and they felt comfortable with the candidate (Humphrey & Lewis, 2008a). This involved getting to know each student at their home by engaging in activities of interest to them, for example playing with the family dog.

4.2.7 Interviews

Interviews were conducted between May 2011 and January 2012. Parent interviews were conducted first, between May 2011 and November 2011. Figure 4.1 provides a visual representation of the interview process with parents.

Figure 4.1: The interview process with parents



First round interviews with parents

Interviews were conducted in private homes at dates and times that were convenient to the participants. All interviews were recorded on a digital recorder. Each parent was interviewed on two occasions (18 interviews in total). At their first interview a parent from each family was asked to complete a demographic form about themselves and their child. The information collected about parents included age, gender, ethnicity, employment status, occupation, education, and marital status (Table 4.1). The information collected about students included their age, gender, ethnicity,

diagnosis, school year level, type of school (e.g. state, catholic, independent, special school or home school) and enrolment status (e.g. full-time or part-time).

A parent from each family also completed a Krug Asperger's Disorder Index (KADI) (Arick & Krug, 2003) in relation to their child. The purpose of administering the KADI was to verify each child's diagnosis. The KADI begins with a pre-screening scale that separates out the normal population. The KADI is composed of 32 items. Each item on the KADI has a weighted score that reflects its ability to differentiate Asperger's disorder from high functioning autism and the normal population. Raw scores are converted to percentile and standard scores. It took parents an average of 15 minutes to complete.

The KADI was selected in this study as the majority of the students in the sample had a diagnosis of Asperger's Disorder and a review of five rating scales for screening and detection of Asperger's Disorder by Campbell (2005) indicated that it was the most sound in terms of reliability and validity. However, there were limitations to the use of this test in the context of this study. Several of the student participants had been previously diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified and consequently did not score highly on this test for Asperger's Disorder. Although the test is purported to distinguish between Asperger's Disorder and other forms of High Functioning Autism (Arick & Krug, 2003) it cannot be used to confirm a diagnosis of these other forms of ASD. Despite the limitations of the use of the KADI in this study, the test did provide useful contextual information on the functional status of each of the students in this study.

Table 4.4: KADI scores for each student participant

Student pseudonym	KADI standard score (0-130)	Likelihood for Asperger's disorder diagnosis (very low - very high)
Paul	68	Very low
Claire	91	High
Luke	89	Somewhat likely
Beth	102	High
Brad	102	High
Jake	81	Somewhat likely
Rhys	100	High
Brendan	84	Somewhat likely
Declan	85	Somewhat likely

The first parent interview focussed on obtaining a broad overview of their perceptions of children's participation in primary and secondary school and the key events along this timeline (Appendix 8). Topics in the first interview guide were used to prompt participants, however, this was used flexibly to also allow parents to raise topics of interest and importance to them in relation to their children's participation. The length of the first parent interviews ranged from one and a half to three and a half hours. Although the intention was to interview one parent from each family (9 parents in total), in two cases a second parent was present during the interview and contributed their perspective (final sample n = 11 parents). Consequently a pragmatic judgement was made on the ground to complete these interviews with both parents present and consent from the second parent was obtained in these two instances at the end of the interview. While this was not ideal in terms of ethical requirements it highlights the unpredictable nature of fieldwork and need to respect potential participants' involvement especially when one is in participants' homes. For a detailed discussion of ethical dilemmas faced by researchers in the field see Pollock (2005). Since the unit of analysis was an individual parent, not couples, these parents' perspectives are represented individually in the results chapters.

These first round interviews were then transcribed in full by the candidate. This informed the development of a second semi-structured interview guide to be used in a targeted follow-up interview with each parent. The second interview guide was divided into four sections. The first section explored parents' perceptions of changes in their children's education since the last interview. The second section involved clarification and provided a chance for parents to provide further detailed information on their perceptions of their children's participation. In order to capture the life course concepts of human agency and linked lives, this section also investigated how parents had advocated for their children and about the psychological, social and financial impacts they experienced in supporting their children's participation over time. The third section focused on their perceptions of children's future education. This was intended to capture parents' perceptions of cumulative processes, that is, their perceptions about how their children's early experiences of participation in education might influence their participation in further education. The final section asked parents about their perceptions of the ideal education for their child (Appendix 9). This was intended to capture the meaning of inclusion to them. Before the second interviews a trajectory grid which captured each student's participation trajectory was also developed for each student based on the information from the first parent interview (see Appendix 12 for an example). These trajectory grids were then presented to parents in their second interviews.

Second round interviews with parents

A second interview with each parent was conducted four to eight weeks after their first interview and at a time convenient to them. Interviews were conducted at their homes and were digitally recorded. In these interviews the trajectory grids and the second interview guide were utilised flexibly to probe the themes of participation more extensively. These interviews provided opportunities to develop a relationship with parents, which may have been important so that they felt comfortable to talk about sensitive topics (Vincent, 2012). They provided opportunity to: (a) obtain further information, (b) follow up topics that were not discussed in the first interview, (c) clarify issues discussed in the first round of interviews, and (d) seek feedback and verification on the interpretation of these issues (Vincent, 2012). The length of the second parent interviews ranged from one and a half to three and a half hours each.

The trajectory grids proved to be a useful data collection tool in the second interviews as these provided a concise visual summary of each student's participation trajectory to present to parents. They also facilitated member checking for accuracy and allowed clarification of information and additional detail to be included (Wilson et al., 2007). For example, parents were asked: "Looking across this trajectory at your child's experiences in primary and secondary school, to what extent do you think he/she has had an inclusive experience so far?". After the second interviews the trajectory grid for each student was corrected where necessary and additional information was added.

There were also unexpected emotional consequences of using the trajectory grids during data collection. Three parents commented that viewing their child's participation trajectory was confronting as is illustrated in the following excerpt from Laura:

"It's almost a little bit confronting, it's like that's our whole life there really, that pretty much sums everything up, it's all the things you think about and remember but to see it all there is yeah"
(Laura).

It appeared to be particularly confronting for parents when the trajectory grid illustrated that their child had participated very little over the course of their schooling. Thus sensitivity was necessary in the use of the trajectory grids.

Student interviews

One interview with each student was undertaken (eight interviews in total). These interviews occurred after their parents' interviews were completed. The interviews took place between September 2011 and January 2012 and occurred in the student's homes. The purpose of the student interview was to explore their own perspectives, experiences and responses to participation in mainstream school (Appendix 10). Interviews with the students lasted between 30 and 70 minutes.

4.2.8 Facilitating the participation of the students in the interviews

This section critically reflects on utility of the strategies used to facilitate the participation of the students in their interviews (for a more detailed discussion see Harrington et al., 2013)². Students were given the option to have a parent present during their interview. Seven of the eight declined the offer of having a parent present. The presence of a parent yielded strengths and limitations. The one parent who was present was able to assist her child to respond to questions by providing memory prompts; however the parent interrupted and corrected their child if she felt her child's response was inaccurate. In seeking to address the parental influence during the interview questions were deliberately re-directed back to the student and to gain his perspective and to check whether he agreed or disagreed when his parent answered a question on his behalf. This strategy had some success, however sensitivity was required on the part of the candidate to recognise how often redirection could be used as the candidate wanted to ensure that the parent did not feel their perspective was unimportant.

A written schedule that incorporated pictures was used in the interviews to indicate the sequence of events in the interview (Appendix 11). The students all seemed to respond well to this schedule, as they knew which topics had been covered, and which were yet to be discussed. This appeared to help maintain their concentration during the interview. Prior to commencing their interview the schedule was explained to them and was then used as a prompt throughout the interviews.

One student had limited verbal communication, with one to three words on average and difficulty verbalising feelings when asked about the bullying he experienced at school. The Picture Communication Symbols™ enabled him to express how he felt - sad, lonely and angry. Drawings were used in addition to verbal narrative in this student's case (Appendix 13). The students were also provided with a pictorial 'break card' which could be used if they wanted to have a break;

² This section of the chapter presents content adapted from a previous publication by Harrington et al. (2013).

however none of them chose to use it. They also had a pictorial ‘stop card’ that they could use if they wished to terminate the interview. While none of them chose to use the ‘stop card’, in some cases their non-verbal cues gave the researcher an indication that they were restless and that their attention may be waning. Hence the interviews were concluded soon after so as to not cause them discomfort or further fatigue.

In seeking to elicit the views of students it was necessary to understand each of their communication capabilities and to use strategies to facilitate communication. There was considerable variation in how the students communicated. Therefore the candidate’s verbal communication style was adjusted to accommodate each student’s communicative abilities. This involved attention to: simple language; avoidance of ambiguous language and figures of speech; concrete examples; clarity of questions; and checking the accuracy of interpretations. However, occasionally some questions were ambiguously phrased and participant’s responses indicated that they had misunderstood the meaning.

Two of the students displayed delays in processing language and took substantial time before they responded to the interview questions. For example, Paul took up to 11 seconds before responding to each question. To address this extra time was given to allow him to process the question before proceeding to the next question. This appeared effective as responses were forthcoming when adequate time was provided. The validity of long pauses to encourage a response from young people with communication impairments is supported by other research (Lewis, 2001).

Since young people with ASD often have special interests that are exceptionally intense and which can absorb their attention it was anticipated that it could be difficult to keep the students on topic and that they may digress and talk unremittingly about their special interests during their interviews. However, this only occurred with one of the eight participants. This young male participant’s special interest was movies. Numerous times throughout his interview he steered the discussion onto this topic. This was addressed by allowing time to talk briefly about his interest, without further encouragement through questions, and then re-directing his attention back to the next interview question. This strategy was successful as it enabled him to get back on topic, however it needed to be repeated each time he steered the discussion to his special interest. Owen, Hayett and Roulstone (2004) used a similar strategy in their research with children with communication difficulties. They reported that allowing the children to briefly discuss their interest seemed to result in a longer period of active participation for them.

Overall, engaging the students with ASD in the interviews was challenging. However, the

successful use of creative and flexible strategies enabled them to express their views. This demonstrates that if given the opportunity, and the appropriate supports, they can provide rich and valuable insights into their own experiences (Harrington et al., 2013).

4.2.8 Honorarium

All participants received a small honorarium in recognition of their contribution to the research. They received this at the end of their interviews. Parents were given \$25 and students were given \$15. The practice of paying participants is debated in the literature (Head, 2009). Some argue that monetary incentives might be viewed as inducement and be exploitative (Paradis, 2000). While the potential ethical issues surrounding payment of participants were recognised, the honorarium provided a way to acknowledge the contributions of parents and students to the research both in terms of time and content.

4.2.9 Field journal

A field journal was used to record field notes during data collection. Entries into the field journal were made immediately after every interview. The field journal had several uses. It was used to record additional observations and contextual information; and to document initial impressions of the themes. It was also used to record personal reactions, reflections and learning about the interview process. This learning facilitated improvements in the candidate's interview skills as the data collection progressed. The journal also provided a place to store questions raised by the first interviews for follow up in the second interviews with parents.

4.2.10 Data transcription

All interviews were transcribed in full by the candidate. Transcription was verbatim and included the emotional responses of participants where they were clearly discernible. For example, when a participant could be heard crying, laughing and so on it was recorded in brackets e.g. (laughs). Transcripts were de-identified and pseudonyms were used. Parent transcripts averaged 30 double-spaced pages in length. Transcription produced a total of 500 double-spaced pages of parent data. Student transcripts averaged 20 double-spaced pages in length. Transcription produced a total of 160 double-spaced pages of student data. Data memos were made during the transcription process with the aim of recording the candidate's emerging impressions of the data and any observations about the commonalities and differences across the data.

4.2.11 Data analysis

The aim of the thematic analysis was to describe participation in mainstream schools across the schooling years and to understand the meanings associated with the participation of students with ASD in mainstream over time from the perspectives of students and their parents. The analytic approach was inductive and thus concepts from Life Course Theory were explored within the data towards the end of the analysis. The framework for thematic analysis developed by Braun & Clarke (2006) was used to structure the analysis of both parent and student data. Table 4.5 provides description of the six phases of this framework.

Table 4.5: Phases of thematic analysis (reproduced from Braun & Clarke, 2006, p. 87)

Phase	Description of the process
1 Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re- reading the data, noting down initial ideas.
2 Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3 Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4 Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis.
5 Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6 Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Parent and student data were analysed separately, with the analysis commencing with the parent data first. The first and second interview transcripts for each parent were treated as one data source during analysis. Analysis of parent data was used to answer three of the four research questions:

1. How do parents perceive and make sense of their children's participation in mainstream school over time?
2. What are the participation trajectories of students with ASD attending mainstream schools?
3. What are parents' experiences of supporting their children's participation in mainstream school over time?

The application of the framework for thematic analysis (Braun & Clarke, 2006) to the parent data is described in detail below.

1. Hardcopies of all parent transcripts were read several times to develop familiarity with the data. Notations were made in the margins to formulate initial impressions of each participant's perceptions and experiences of participation.
2. NVivo (QSR International Pty Ltd, 2010), a qualitative software package was used to manage and organise the data on the computer. All transcripts were imported into NVivo. Further coding was then conducted in NVivo. Consistent with an inductive approach the codes remained close to the verbatim data. One transcript was coded in NVivo by the candidate and by one thesis advisor, who then met, to discuss discrepancies and finalise a coding framework (see Appendix 14). This was then systematically applied across the entire parent data set. Where new codes emerged these were added to the coding framework and applied across the parent data set. This produced a large number of descriptive codes that needed further abstraction.
3. From the already established coding framework a series of thematic charts were constructed in Microsoft Word™ that summarised the data linked to each code. The technique for constructing thematic charts developed by (Ritchie, Spencer & O'Connor, 2003) was used. In this method each participant is assigned a row in the chart, and each code a column. All of the participant quotes linked to each code are then inserted into the relevant column. When transferring the data to the charts Ritchie et al. (2003) encourage retention of the context and language in which

the data was expressed so that the data does not become de- contextualised. This required judgments to be made about how much content to place in the charts – enough to retain the context but not so much that it became unmanageable. This process of synthesising the data in charts allowed for further analysis.

Two sets of thematic charts were developed. The first chart incorporated the codes related to parents' perceptions of their children's participation in mainstream school over time (research question one) and the second incorporated those related to parents' experiences of supporting their children's participation in mainstream school over time (research question three. See Appendix 14 for an example). Once the thematic charts were developed the analysis focused on searching for repeated patterns of meaning across each chart. This involved moving beyond descriptive codes about what participants said to interpret the meaning behind them. This led to the generation of an initial set of themes related to each research question.

4. All of the data collated under each theme were examined to ensure each theme represented a coherent and distinct pattern of meaning in the data. During this phase memo writing was used to reflect further about the initial themes (see Appendix 14 for an example). The diversity of perceptions and experiences related to each theme was noted. This led to identification of the dimensions of each theme (the sub-themes).
5. This next phase involved identifying the 'essence' of what each theme was about (Braun & Clarke, 2006). It involved writing a final description of each theme and the sub-themes. Table 4.6 provides an example of the process of theme development. At this stage concepts from Life Course Theory were explored in the themes. These included: timing, linked lives, human agency, turning points, transitions and cumulative processes. The application of these concepts enabled deeper interpretation of the themes.
6. Analysis was not a distinct phase, but rather was continuous throughout the research process. Therefore during the writing of the results further clarity was gained about the themes and the final themes were refined through the writing. At this stage a summary of the themes was emailed to each parent for the purposes of member checking. Only one parent responded, reporting that the themes corresponded with her individual perspective and experience. At the final stages of writing, the themes were related to pertinent literature in the field. The themes related to parent perceptions (research question one) are presented in chapter five and those

related to parent experiences (research question three) are presented in chapter seven.

In order to describe the participation trajectories of the students (research question two) the candidate analysed the themes developed about parents perceptions of students' participation in mainstream school across the schooling years to identify patterns of participation over time across the student group (participation trajectory types). Life course theorists term these 'constructed trajectories' as they are constructed by the researcher, rather than empirically derived and are used by qualitative researchers to examine patterns over time (George, 2009), in this case participation patterns. The candidate then selected two students whose participation best exemplified these two different trajectory types and wrote in-depth stories based on their parent interview data that described their participation trajectories. The trajectory types and in-depth stories are presented in chapter six.

The framework for thematic analysis (Braun & Clarke, 2006) was also used to analyse the student interview data. This generated a set of themes to illustrate their current experience of participation in mainstream schools (research question four). These are discussed in chapter eight.

Table 4.6: Example of theme development

Data excerpt	Descriptive code	Theme	Description of the theme	Sub theme
<i>Hayley: It was just constant you know and if you didn't become an advocate you'd lose your son or your daughter because you can't always have the school being right you know and the school's never going to develop if they aren't told some of the truths that they need to hear.</i>	Advocacy	Perpetual battle	Parents experienced a perpetual battle over time. Parents expected mainstream schools to provide appropriate educational provision that met the changing needs of their children over time. However there was often a discrepancy between these expectations and what they perceived was actually provided to their children in mainstream schools.	Constant advocacy

4.2.12 Rigour

A number of strategies were employed to ensure methodological rigour in this study. All interviews were conducted and transcribed by the candidate to ensure consistency. The approach to analysis was systematic. The framework for thematic analysis (Braun & Clarke, 2006) was applied to both the parent and student data. The coding process was thorough and comprehensive with all of the data being given equal attention. One thesis advisor co-coded a parent transcript and agreement was formed about the coding framework before it was applied to the entire parent data set. This process was also undertaken for the student analysis. Attention was given to negative-cases during analysis and in the results chapters a range of realities are captured to reflect the variation of perceptions and experiences among the parent and student participants. An audit trail was kept to document the process of decision-making used to develop the themes. During the period of analysis, regular supervision meetings focused on discussion of the emerging themes. This provided an opportunity for the thesis advisors to examine the audit trail, for example the thematic charts and data memos and to propose alternative interpretations where these occurred. This feedback was then incorporated to further develop the analysis.

Member checking was used to compare the candidate's interpretations of the themes with those of the parent and student participants to determine the level of correspondence between the two (Mays & Pope, 2000). As mentioned earlier in the chapter, the trajectory grids acted as a tool for member checking with parents at the beginning of their second interviews. They enabled clarification with parents and for any inaccuracies to be corrected at this stage. Member checking was also undertaken at the end of the study with parents and students. All participants were sent a summary of the themes and were asked to report on their accordance with their perceptions and experiences. Only one parent responded and reported that the themes corresponded to her individual perspective and experience. None of the students provided feedback on the relevance of the themes to their individual perspectives and experiences.

Reflexivity was also employed throughout the study, with sensitivity to the ways in which the candidate's prior assumptions and experience shaped the research process (Mays & Pope, 2000). Prior to commencement of the thesis, the candidate had been employed in a social work position at AQ for two years, working with both students with ASD and their parents. As a result, the candidate had been exposed to parents and students whose experiences of participation in the mainstream education system were primarily negative. This may have focused attention on the negative experiences of the participants in this study. To address this potential bias a reflective

journal was kept by the candidate throughout the period of data collection and analysis to record reactions to the data. The interview schedules were also designed to include questions about positive experiences of participation in mainstream schools. As mentioned earlier, peer checking was also regularly undertaken with advisors, which provided opportunity to discuss interpretations of participants' stories and to develop alternative explanations. Member checking was also completed to ensure accordance between participants' interpretations and those of the candidate.

Although qualitative research is not intended to produce results that are generalisable to a wider population it is still required to be able to demonstrate the transferability of the results to other contexts (Kuper, Lingard & Levinson 2008). To enhance transferability in this study thick description of the context of the participants has been provided through use of tables of participant characteristics (See tables 4.1 & 4.2). Additionally, throughout the results chapters the results are discussed with reference to the published literature and similarities and dissimilarities are noted.

4.2.13 Disseminating the findings

A summary of the themes was emailed to each parent and student participant at the end of the research process as a way to provide feedback on the results of the study. The findings have also been disseminated to the field. The methodological contribution and the results of the study have been presented at four conferences in the past two years, three of which were international. They have also been presented at a number of local research forums and teacher training days, all of which were attended by a mix of practitioners such as teachers, psychologists and principals working in the field as well as academics. Attendees at these events expressed interest in the research, acknowledged its importance and requested access to publications of the results. Publications of the results in academic journals are forthcoming.

4.3 ETHICAL ISSUES

Prior to the commencement of fieldwork ethical approval was granted for this study by the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland (Appendix A). Two ethical issues require examination: anonymity and non-maleficence.

4.3.1 Anonymity

A number of steps were taken to protect the anonymity of the participants. Data were de-identified and stored in a locked filing cabinet in the School of Social Work and Human Services at The University of Queensland. Although AQ acted as a gatekeeper, precautions were taken to ensure the

organisation was not aware which clients were participating. Consequently, potential participants were asked to contact the candidate directly. Maintaining their anonymity was imperative as students or parents might have had concerns about speaking negatively about the education system for fear of further exclusion. They were informed that the study was independent of Education Queensland and AQ and their participation in the research would not affect their access to services. It must be acknowledged that full anonymity cannot be assured in the publishing of qualitative research as biographical details can lead to inferred identification (Swain, Heyman & Gillman, 1998). In the Participant Information Sheet For Parents (Appendix 3), participants were informed that the results of the study would be published in academic journals and presented at conferences and they consented for their information to be used in this way. They were also made aware that pseudonyms would be used in all published material.

4.3.2 Non-maleficence

Researchers have an ethical responsibility to minimise distress to participants (National Health and Medical Research Council [NHMRC], 2014). It was acknowledged from the outset that asking participants about their experiences of participation in mainstream school could lead to a discussion of sensitive topics that may cause emotional distress. Therefore during the interviews it was important to be attentive to signs of discomfort and to check if parents or students needed a break or to stop their interviews. Some parents did become upset at times during their interviews. They found it particularly confronting when they were asked: “what does the future hold for your child?” Many parents responded by expressing fears and concerns about their children’s future prospects and felt that their children may never achieve independence and may struggle to participate meaningfully in society for the rest of their life. Some parents said that these fears were so overwhelming that they have to stay focussed on the present in order to cope. It was assumed that because parents were recruited through a gatekeeper organisation (AQ) that they might already be accessing emotional support through that organisation. However, this was not always the case. Some of the parents found the interviews upsetting at times and since the candidate could not perform the role of counsellor, this needed to be attended to outside the research relationship. Therefore, parents were provided with an information sheet that listed counselling and advocacy options if they required it.

Students did not exhibit distress during their interviews. They were offered a break card and stop card that they could hand to the candidate if they wished to have a break or to terminate their interview and were not able to explain this verbally. All of the students completed their interviews with none electing to use either of the cards.

4.4 CHAPTER SUMMARY

This chapter has described the rationale and approach to the qualitative study employed to explore the perspectives and experiences of students with ASD and their parents about participation in mainstream school over time. The methods used in this study proved to be innovative in two ways. Firstly, practical and creative strategies were developed and used effectively to enable the participation of the students in their interviews (see Harrington et al., 2013). Secondly, the trajectory grid technique was adapted from life course grids (Parry et al., 1999) to chart the participation of the students over time and proved a useful data collection tool in the parent interviews. This chapter has also critically reflected on the rigour of the study and the pertinent ethical issues and has described how these were addressed. The next chapter presents the first of four results chapters. The chapter will report on parent perceptions of their children's participation in mainstream school over time.

CHAPTER FIVE: PARENT PERCEPTIONS OF PARTICIPATION ACROSS THE SCHOOL YEARS

This chapter describes how parents perceived and made sense of their children's participation in mainstream school over time. It uses the data obtained from the first and second parent interviews. The chapter presents three principal themes: 'restricted participation', 'variable impact of school staff' and 'turning points'. Quotes are used to demonstrate the themes. The selected quotes are representative of parents' perceptions. Pseudonyms are used to protect the identity of the participants.

5.1 THEME ONE: RESTRICTED PARTICIPATION

Taking account of their child's whole of school experience to date, the dominant perception of parents was that participation in mainstream school was characteristically 'restricted participation'. Parents described a partial or less complete participation in both the social and academic activities of mainstream school over the course of their children's schooling. The following excerpt captures this overall sentiment:

"He's never really fully participated in school, I think that would be the thing that stands out to me the most" (Hayley).

From parents' perspectives, although restricted participation occurred most often in relation to both the social and academic activities of mainstream school, there were distinct examples where it involved the social aspects of school only. Notably, the social aspects of participation were not limited to being *at school*, rather parents' evaluations of participation in mainstream school extended to the social relationships and processes that developed from school, for example, participation in outside social events with their peers from mainstream school. In all cases, however, parents perceived that restricted participation was the result of student-related factors and the school environment and the interactions between these.

5.1.1 Sub-theme one: Restricted social participation

All parents perceived that their children's experiences over time was characterised by restricted social participation. There were three aspects to this: limited friendships, poor sense of belonging and limited participation in school social activities. Parents universally reported that their children had limited friendships. A few parents reported that although their children had friends in early

primary school, they had not maintained them over time. However, the majority of parents reported that their children had never had friends or had very few friends at school. For example, Glen said:

“Brendan has never had many friends and through school he really only ever had one friend” (Glen).

Most parents reported that the few friends their children did have tended to be other students with disabilities, rather than their typically developing peers. For example, Laura said:

“His friends weren’t normal kids, they were other SEU kids, he has got one friend that is not in the SEU, but he’s a little eccentric” (Laura).

Parents’ reports also indicated how restricted participation in mainstream school spilled over to impact on social participation in both school-related activities and activities external to school; however, parents did not distinguish these as such, rather they viewed this as all part of poor participation in mainstream school.

All but one parent provided examples of mainstream schools restricting their children’s opportunities to participate in school-related social activities, which they perceived impacted negatively on their children’s social participation. In some instances this appeared to be linked to a behavioural management strategy. For example, according to two parents their children were reportedly not allowed to access the playground at all during break times in primary school. They had to remain in the special education unit and had no contact with their mainstream peers during breaks. For example, one of these parents said:

“Because there had been some outbursts at lunchtimes they basically pulled back his ability to go out into the oval environment. He was told ‘no for lunches you are now at the SEP and that was pretty much grade 5, 6, and even some of grade 7” (Glen).

There was some indication from parents that participation restrictions in school-related activities was linked to perceptions of risk and lack of resources. For example, one parent reported that her son was excluded from participating in a range of social activities at multiple mainstream schools as they didn’t have the staff to supervise him:

“All the mainstream schools would never let him go on a camp, even excursions, he was not allowed to attend excursions, they didn’t have the people... their sports days he was never allowed to attend until [name of special school]. The fetes and things like that he was never

asked to man a stall with people. Even awards nights and things like that, if there was something to give him they would send it home with him, he was never formally invited to anything like that" (Anna).

In another example, Glen described the response he received from a staff member at his son's state primary school when he raised the idea of Brendan attending school camp in year five:

"We don't know if we have the resources to be able to manage him in that environment and because he's been a run away at school and if he runs away..." (Glen).

Consequently, Brendan was unable to attend the camp. In contrast, a few schools did include students in school activities such as school camps and sports. In this example, Hayley reported that at her son's (Declan) independent secondary school they had included him in the year 11 camp and in school sports. The school facilitated his participation in sport by offering activities that interested him.

"[School name] has been quite inclusive, they've always tried to get him to do sports and do the stuff that he doesn't feel comfortable with and it has been good there cause they do other sports like that laser skirmish that he will participate in" (Hayley).

The differences between Brendan and Declan's social participation could indicate varying levels of commitment in their schools to facilitating the social participation of students with ASD. It could also relate to differing levels of resources as Brendan attended a state school, whereas Declan attending an independent school that was reportedly expensive to attend and thus the school may have had more resources to support students with disabilities.

Parents perceived that student factors, in interaction with the school environment, also contributed to their restricted social participation over time. Parents universally reported their children had social skills difficulties that significantly impacted their ability to participate socially at school as illustrated by Sarah:

"She so desperately wants to be a part of it all and she just can't break in, it's like the door is locked and she just has not got the keys to do it and we've tried everything to give her the keys but it's just not within her, she just doesn't know how to" (Sarah).

These social skills difficulties were not perceived to have been adequately supported in any of the mainstream schools. Parents reported the social skills support offered in mainstream schools was either insufficient or non-existent as Hayley described:

“They don’t get a lot of life skills at school; they don’t get social skills you know. I guess they can get social skills from school but they don’t really get taught them at school, they’re there but they don’t get taught them” (Hayley).

There was a significant gap between the social skills support offered in mainstream schools and what parents perceived their children needed and this contributed to their children’s restricted social participation. Parents felt social skills were important for participation, and more broadly for leading a good life, and they wanted them to be taught in mainstream schools. Parents reported that a motivating factor in enrolling their children in an ASD-specific placement was to redress this gap in provision. They also accessed private psychologists to address their children’s social skills difficulties. This suggests parents have to seek supplementary programs in the private sector to meet their children’s needs (McDonald, 2010). In a number of previous studies parents have acknowledged the importance of social skills and reported that social skills training is a significant a gap in provision in mainstream schools (Batten et al., 2006; Brown et al., 2012; Reid & Batten, 2006; Rowley et al., 2012; Spann et al., 2003). This is concerning as students’ social relationships with peers may be improved through providing social skills training to students with ASD in mainstream schools (Batten et al., 2006; Brewin et al., 2008).

Several parents perceived that their children actively chose not to participate in sporting activities as they were difficult for them to perform well in. These students may have been concerned about standing out if they performed poorly in these activities and so they avoided participating in them. For example, Sue reported that although her son Rhys had previously participated in sports carnivals in early primary school, as he aged he became self-conscious of his sporting difficulties and consequently he refused to participate:

“The first year or two of primary that was okay and he competed and everything but then his confidence just started going you know because he realised well I don’t run as fast as the other kids cause his motor skills weren’t the best...so he knew he was lacking there and if he couldn’t be the best or one of the better ones then he didn’t want to know about it you know” (Sue).

In Rhys’s case there appears to be two reasons why he was deterred from participation. Sue

perceived that Rhys did not want to participate if he could not master the activity. A number of other parents also provided examples of their children refusing to participate if they could not be the best. This could indicate perfectionistic beliefs that have found to be present in children with ASD and can lead to increased anxiety (Greenway & Howlin, 2010). Sue also perceived that Rhys had difficulties with gross motor skills. Gross motor problems are an associated feature of ASD (Fournier et al., 2010). Therefore many students with ASD may experience difficulties participating in physical education. There is a need for schools to find alternative ways to include students with ASD in physical education. For example, by being the umpire of a game, or engaging in non-competitive physical activities.

Restricted social participation was not limited to school-related activities as there were many examples where it spilled over to external activities. Parents reported that their children had rarely been invited to peers birthday parties or play dates throughout their schooling. Although some children had received invitations and attended some birthday parties in early primary school as they progressed into later primary school and secondary school this became rare. Parents reported that when their children reached adolescence they became aware that not participating in these social activities was atypical and this led to a perception of difference from their peers as Hayley indicated:

“He’s never asked to go to the movies or go out with the boys or anything and that should be sort of happening at that age. Never been asked to a party... I guess he sees all that sort of stuff and realises he’s not the same as other people. So I would say that yeah he’s never really fitted into that system” (Hayley).

This was likely linked to a lack of belonging. All but one parent perceived that although their children desired belonging they had not experienced a sense of belonging in their mainstream schools. For example, Hayley described her son Declan’s poor sense of belonging:

“I don’t think he really feels included, I think he knows he’s different and he’s in an environment where there’s a whole heap of people that are similar and he’s the odd one out. It would be very hard for him to feel part of that and I don’t think he ever really has you know” (Hayley).

In the one exception, although her son Brad did not necessarily have a sense of belonging, this parent perceived this was due to his personal preference regarding social contact:

"He's included as much as what he wants to be included you know and I think if he wanted to be included a lot more he could be. I don't think like, I walk around with him, even at his primary school or we go to [name of shopping centre] or something and there's always kids walking past going 'hey Brad' you know all the time and so to me that's a positive thing you know, it's not sort of like avoiding or going, but they're like 'hey Brad'... and he's actually the one who's not saying hello back kind of thing" (Jemma).

It is plausible that Brad's restricted social participation could have been due to his lack of desire for social contact as his mother perceived. In a previous study in the United Kingdom Calder et al. (2012) investigated the extent and nature of the friendships of twelve students with ASD from their perspective and from those of their mothers, teachers and classroom peers using a combination of quantitative, qualitative and social network methods. Calder et al. (2012) reported that students were found to vary in their desire for social contact. However, an alternative explanation is that Brad desired social contact with his peers but had difficulty socially interacting with them due to his ASD as this is a core difficulty for people with ASD (APA, 2013).

Parents made sense of their children's restricted social participation as being the result of a combination of school and student-related factors. Firstly, parents perceived that mainstream peers for the most part had not accepted their children's differences. For example Glen said:

"Socially he didn't really go well with groups or peers because he was considered different or targeted as being different by the kids so from the peer point of view he wasn't as accepted" (Glen).

This lack of acceptance of difference led to bullying. Parents universally reported that their children experienced bullying at some point in their schooling, including: ostracism, teasing, being goaded and physical assault. The forms of bullying, severity and duration varied from student to student. For some it was constant, for others it stopped when they changed to a different school. The following excerpt from Glen indicates the multiple forms of bullying his son Brendan experienced in primary school:

"In the primary school he was set up a few times knowing they could spark him off and that will set him going and they knew that would get him in trouble... there was one time where Brendan had...we did have the school ring us and say Brendan has been hit by someone" (Glen).

Bullying was no longer perceived to be an issue since Brendan had begun secondary school at a

new school. Glen remarked: “seems to have settled down now that he’s gone to high school and maybe once again cause he’s not at high school 5 days a week.” It appears that Glen perceived there were fewer opportunities for Brendan to be bullied as he only attended mainstream school two days per week and attended an AQ placement on the other three days.

Several parents whose children had experienced severe, prolonged bullying believed it had been the most harmful experience for their children in mainstream schools as Sarah indicated:

“Bullying has been the biggest thing, the biggest thing... She just has no friends at all. So no one talks to her at all, so it’s either one or the other, she’s either bullied relentlessly or everyone just pretends she doesn’t exist. You know and then she’s lonely and all by herself” (Sarah).

These findings are supported by the extant literature in which high rates of bullying in mainstream school have been reported by parents of children with ASD (Batten et al., 2006; Cappadocia et al., 2012; Chen & Schwartz, 2012; Humphrey & Symes, 2010; Little, 2002; Reid, 2011; Reid & Batten, 2006; Rowley et al., 2012) and serious, negative impacts as a result of bullying including: reduced self-esteem and social skills (Batten et al., 2006), mental health difficulties (Batten et al., 2006; Cappadocia et al., 2012; Hebron & Humphrey, 2012; Penney, 2013), and suicidal feelings and self-harming behaviour (Batten et al., 2006).

5.1.2 Sub-theme two: Restricted academic participation

The majority of parents reported that overall their children had experienced restricted academic participation over the course of their schooling. This involved: limited academic engagement, exclusions from the classroom (which meant reduced opportunities to participate in the curriculum), suspensions and poor academic progress.

In an example that typified this theme, one parent (Anna) perceived that the school used exclusion from the classroom as a management strategy. In this example, the parent perceived the school could not manage her son Paul’s behavioural issues at school and thus reduced his hours of attendance.

“He was excluded from the classroom a lot because the behaviours were high... [his hours were] gradually decreased until it got ridiculous which was 1 hour 10, 1 hour 20 minutes [per day] – that’s not education and that was when he was by himself with a teacher so that is not inclusion” (Anna).

In contrast, two parents reported that their children had fairly stable academic participation throughout their schooling. In these cases this appeared to be due to both student characteristics, such as their academic ability, and the willingness of their schools to make accommodations to support their academic participation. One of these parents, Jemma describes her perception below:

"I think he's been really lucky because he has had teachers that have cared and willing to help, I think he's been lucky that he's been born into a family that could afford to get him a tutor" (Jemma).

This excerpt also highlights an additional, potential factor in participation, that of, family resources. The extent to which financial resources can facilitate opportunities for participation, albeit through private means in this case, is of interest since it generates questions about what can be expected of families and how to ensure a fair and equitable opportunity for all students.

For the seven students who had restricted academic participation all but one of their parents perceived it was the result of a number of environmental factors. Firstly, parents perceived that the curriculum, pedagogy and physical environment were one-size-fits-all and tailored to the 'average' student. For many students this was at odds with their learning styles, sensory profiles and organisational skills and this led to reduced participation as illustrated by Sarah:

"They tend to only teach one way ...usually it's you know teacher in front of a blackboard doing it on the blackboard, here's your textbook, do the work. And she just can't focus with other people in the room ...having to have all of her pens and pencils, the organisational skills you need, everything about the school day excluded her. Like if you have a serious lack of organisational skills you can't participate in a subject in a school day. Everybody knows that they need to have a pencil case and a pencil and a rubber, well not Beth, or the right books" (Sarah).

For the most part parents perceived that schools had expected their children with ASD to conform to their one-size-fits-all model. In an example representative of this perception, Philip perceived his daughter's experience was the consequence of a greater agenda –the reproduction of the 'norm'.

"I still think their goal and their thrust is to fit them in with the mainstream and make them normal. It really, really just try to make them normal by different means, they really still don't accept them as different... for what they are...they just keep at this funnelling in the bottle, funnel, all got to go through that funnel, doesn't matter what side of the spectrum,

“they’ve got to fit...And they want her to go down the funnel and be like everybody else, and it’s not going to happen” (Philip).

This was problematic, as parents perceived their children were unable, rather than unwilling to conform because of their disability as Anna reported:

“[The schools say] why won’t he fit in? It’s not: how come he is not? Or why can’t he? Why won’t he? It’s like he’s got a choice over it. He’s got no choice. He has no choice to all these things he can’t put up with. He never asked for that, it was given to him. But yeah ‘why won’t he?’ it’s nothing about won’t, it’s can’t” (Anna).

Due to the belief that their children were unable to change, parents viewed it as the responsibility of the schools to make adaptations to fit with their children and while there were examples where modifications had been made to accommodate their children’s needs, these were often not sustained. In the first extract below, Julia emphasises the school’s onus of responsibility. In the second extract, Anna relays how enthusiasm to support her child’s needs waned with the realisation of the resources that were required.

“I think the schools need to learn to adapt to them not make them adapt to the school because they just can’t do it, it’s too much, it’s too overwhelming, it’s too big” (Julia).

“I think people start really enthusiastic and they say yes, yes, yes, we will do that, we will do this. Then [they] realise that it’s every day, it’s every hour you’ve got to do this. I think it gets too hard and I think that’s where it falls down...They might think okay sure talking to mum we might need to do this for three months, but really talking to mum you need to do this forever and that will work” (Anna).

Restricted academic participation was also perceived to be linked to the inflexibility of the schools routines and procedures. Parent’s reports suggest that schools only provided support for special needs once students were diagnosed. Parents stated that they had inquired about obtaining support for their children prior to diagnosis, but were advised that special education supports are contingent on diagnosis as Philip describes:

“I asked about getting her in the special ed unit and they said ‘no we can’t do that until you get [her] diagnosed’ ” (Philip).

Thus the implementation of special needs support was not perceived to be based on students' needs, but rather on the need to follow departmental policy which states that students must have a verified diagnosis in order to be eligible for support (DET, 2013). On average, the students in this study did not receive a diagnosis of ASD until late primary school (year five approximately). This meant that they spent the majority of primary school without special needs support. During this time they were placed full time in mainstream classrooms without any curriculum adaptations and parents perceived they experienced restricted academic participation as a result as Hayley reported:

"He didn't have any funding so he was just in mainstream classrooms expected to do what every other kid did in the fashion that every other kid did. So it must have been quite difficult for him" (Hayley).

There was also inflexibility in relation to responsiveness to behavioural issues. Several parents provided examples of schools being inflexible regarding uniform policies and/or disciplinary practices. This had a detrimental impact on their children's participation when they did not conform to school rules. Parents felt there should be some flexibility for their children due to their special needs. This is illustrated in the following extract from Glen who described the disciplinary practices used at his son Brendan's primary school to manage his behaviour:

"...The way that they were using suspensions as the avenue of trying to correct his behaviour issues where it was to us, yes suspension for the normal part of the school fine, but unfortunately with Brendan and these other kids [with Asperger's] you can't consider them in that light and there has to be exceptions to the rule" (Glen).'

These parents also perceived that their children were blamed for altercations with their peers. This was particularly so prior to their diagnosis when their children were expected to behave 'normally'. If they did not conform they were perceived to be "naughty children" as Glen describes:

"Pre-diagnosis' where you know he was considered one of the, he was a normal child who was just misbehaving and because he misbehaved so much and they couldn't manage him – they had no resources to additionally manage him, that he was, I suppose, labelled one of the bad ones, one of the naughties" (Glen).

Parents also felt that they were blamed for their children's behavioural difficulties and that these were attributed to their "bad parenting". Two parents reported that teachers had suggested they should improve their parenting skills as Hayley illustrated:

“When he got into preschool the teacher in preschool gave me a book to read saying basically that I had bad parenting skills and that I should read this parenting book because he was a naughty boy and he didn’t do what he was asked to do” (Hayley).

Being held responsible for their child’s behaviour by school staff was reported in a Canadian study by Penney (2013) incorporating the perspectives of nine parents of young people with ASD and co-occurring anxiety and/or depression. A possible explanation for blame being attributed to the parents in this study and lack of adaptations for students’ behaviour is attitudinal. Some parents reported that school staff did not believe that their child had ASD and thus were not willing to accommodate their children’s behaviour as Hayley indicates below. Concomitant with this, several parents suggested that schools should investigate the function of the behaviour with a view to teaching students more appropriate behaviour as suggested by Anna.

“Some people have just got a fixed idea that this kid is naughty and there’s no reason for it ...also people’s attitudes to people with special needs, I think that if they can’t look at somebody and see that they’ve got a physical disability then they’re not judged as being special needs you know what I mean so if you’ve got a limp and you slur your words and you’re cross-eyed or whatever people will give you consideration but if you look normal and talk normal and act normal most of the time they think you’re okay and that you’re just bunging it on” (Hayley).

“Look beyond the behaviour, the behaviour is defiance - not doing it, look beyond that and you will get your answers and that’s how you can skill them” (Anna).

At a system level, there was also a mismatch between the special needs support in mainstream schools and students’ learning needs which had negative implications for students’ academic participation. The majority of parents perceived that the special needs support did not match with their children’s support needs in two ways. Six parents commented that their children needed full time one-on-one teacher aide support in the classroom in order to maintain concentration and engagement in learning. They perceived that there was a gap between their child’s support needs and what was offered in mainstream schools as illustrated by Anna:

“I believe that the most they can get is five hours a week which is an hour a day. The school day is what six hours so what do they do for the next five you know?” (Anna).

Anna's extract indicates that support at the school level was limited due to system level policy. The limited support had negative implications for Paul's participation. As will be described in the trajectory chapter, Paul's school hours were reduced to one hour each day at one of his schools as he was only allowed to attend when he had one-on-one support.

Two parents reported that although their children needed one-on-one support, they were uncomfortable with receiving it as it identified them as different to their mainstream classmates. As a result their children rejected the support and were unable to complete the work independently as illustrated by Glen:

"Brendan didn't like being singled out as being the special child that the teacher was there for. So they tried to you know like be a ghost around him like help him where he could but he sort of doesn't want that help as well. He doesn't want to be seen as that child amongst his other kids, you know friends that are in the class there. So even though he definitely needed the help to get the work done, he would refuse it so therefore no work gets done" (Glen).

Several parents reported that teacher aides were sometimes shared across the class rather than one-on-one with their child. This potentially meant that students did not receive support. For example Laura described how her son Luke did not receive support, as he did not ask for help:

"Luke had classes where he might be one of five kids that that teacher aide is looking after and you know because Luke doesn't ask questions, doesn't say 'I need help', the teacher may as well have not been there. You know they're saying that Luke's got a teacher aide but they may as well not really cause he doesn't ask for help and the teacher aide just thinks yep that he's going along just fine, he gets brushed aside" (Laura).

Luke's situation suggests that resources were being stretched in an attempt to meet the needs of multiple students with special needs in one class. The result was that Luke's support needs were not met and he had difficulty participating in classroom tasks.

Although some parents commented on the inappropriateness of special education support offered in mainstream classes, some identified problems with the support being provided in a separate special education classroom as they felt it identified their children as different to their mainstream peers which set them up to be excluded as Anna described:

“Special units are at the back of the school, you have a separate entrance, so you’re already excluded, you’re not walking through the front door...out of sight, out of mind. That’s what I take from where they’ve placed them, why are they at the back? Why wouldn’t they be at the front where they can just walk through the gate and get to their class, but no we give them separate, and that I think sets it up, they’re already different, they’re going in a different entrance... every day it says you’re different, you’re not included in the big school, you’re over here” (Anna).

The students themselves were aware of this difference, and of their peers’ reactions to it. Sarah indicated that it led her daughter Beth to avoid special education class to minimise bullying:

“She is so aware of that, in her year back at school she avoided all learning support even though the provision was there she wasn’t going anywhere near them because it meant that she was constantly teased and bullied and treated differently and had no friends” (Sarah).

Avoiding learning support limited Beth’s participation but may have minimised negative attention from peers. This situation presents a challenge for mainstream schools, as they must find ways to provide support for students with ASD without marking these students out as different.

Another example of support mismatch was in relation to Individual Education Plans (IEPs). It is best practice to develop IEPs collaboratively with parents on a six monthly basis (DET, 2013). Some parents described how IEP plans were not developed at all or were carried over unchanged each semester even though the child was not meeting their goals. This failed to acknowledge the changing needs of the students over time as Hayley reported in the first extract. In such cases, parents perceived that this resulted in goals that were irrelevant and in students not meeting their goals as Sarah indicates below.

“We go along, we set goals and you know then they’re never really followed through and we get back and we do another one yeah. In fact they just sent me the last IEP in the mail and said if you agree with it, sign it and send it back so they weren’t considering changing anything and as far as I’m concerned an IEP is a moving document and it needs to be changed every time you get the opportunity to” (Hayley).

“I’d walk out of every IEP meeting and what used to always blow my mind was that I’d go to the next IEP meeting and they’d have all these reasons why she hadn’t reached the IEP and why it was carrying over” (Sarah).

Three parents also commented on the difficulties mainstream schools faced in implementing an individualised curriculum. For example, Anna perceived classroom structures hampered implementation:

“They have IEP’s, but they’re not individual are they you know. They’re a lot of paperwork but still at the end of the day they can only be as individual as the class can be” (Anna).

Other systemic factors that were perceived to have led to restricted academic participation were related to the educational system. As indicated in the first extract, these issues included large class sizes, limited resources and an increasingly diverse student population. Most parents perceived that mainstream teachers had good intentions to support their children’s participation but were constrained by broader issues in the education system as suggested in the second extract.

“Classes are getting bigger, schools are getting less I think funding, they’re probably getting more but they’re able to do less with it, teachers are more exhausted, classes with this new inclusion policy you’ve got a class like that teacher had five kids with Asperger’s in the class and 25 other students” (Sarah).

“I think they give it their best shot but they’re hamstrung, just go through the motions. I mean there’s probably a lot of good intent; the system kills it you know” (Philip).

A lack of government funding to support schools to make sufficient educational modifications for their children was a further system issue that parents perceived restricted their children’s academic participation. However, some suggested lack of funds was used by individual schools to justify decisions not to make modifications as Julia reported:

[The school said] ‘Oh we don’t have the funding, we don’t have the support, we don’t have this and we don’t have that, we’re doing the best we can’ yeah or ‘we’ll look into that’ (laughs) the amount of excuses that used to come out of them was unreal. It was unreal. There was an excuse for everything” (Julia)

Although most parents perceived that school factors were the main cause of their children’s participation one parent was the exception. Glen emphasised it was his son’s rigidity in relation to non-preferred academic activities that led to his restricted academic participation. The following excerpt from Gary illustrates his son’s rigidity and its impact on his primary school participation:

“Primary school was a huge struggle because he would not participate and no one could find the key to get him to start. If he wanted to do it he would happily do it, if he didn’t want to do it you didn’t have a choice” (Glen).

However Glen acknowledged that although his son continued to display this rigidity in year eight he was attempting academic tasks.

“The feedback we get from the high school is that he’s doing okay... his caseworker at the school says Brendan just sits there quietly, he’s doing his work, he says he has his way of doing things and it’s very structured and rigid and if you suggest other ways he doesn’t accept them... that is a struggle but we seem to be able to manage, just slowly get him to work through something. So it’s not like he’s just shutting down on us but it does take time to move through something that shouldn’t really take that long but he is getting there” (Glen).

During his interview Glen reported that Brendan had a reduced academic load in high school. This may have contributed to Brendan’s willingness to attempt academic tasks. This reinforces the importance of environmental modifications to support student participation.

5.2 THEME TWO: VARIABLE IMPACT OF SCHOOL STAFF

Parents perceived that school staff had a variable impact on their children’s participation over the course of their mainstream schooling. Some staff had improved their children’s participation and others had decreased it. The impact on student participation was different depending on whether they were frontline staff with whom the students interacted daily such as classroom and special education teachers (sub-theme one), or staff in leadership positions such as the Heads of Special Education Units (SEU) and principals whose interpretation of policies impacted on practices at the school for the student (sub-theme two).

5.2.1 Sub-theme one: Impact of teachers

All of the parents recalled a teacher at some point in their children’s schooling that had a significant positive impact on their classroom participation. There were common qualities to these teachers, parents reported that they cared for, and took an interest in, their individual child and accommodated their individual learning needs. For instance, Julia described her son Jake’s year four special education teacher as an “angel” who adapted the mainstream curriculum to his needs.

In this example the parent's perception was that participation was enabled because of the teacher made modifications to respond to her son's needs.

"She adopted their program (AQ) for him and she tried really hard with him and he adored her, absolutely adored her and she worked really hard doing the visual stuff, the drawings, doing the cards and that sort of stuff" (Julia).

"He was happier, he was not so depressed all the time, he was starting to feel safe, he could communicate better, well with her he could communicate better and that sort of thing. He was happy; you could see that he was proud within himself. He enjoyed going to school" (Julia).

All of the parents also recalled at least one teacher at some point in their children's schooling who had a significantly negative impact on their children's participation. There were common qualities to these teachers, parents reported they lacked understanding of ASD, were inflexible and thus did not accommodate their children's individual learning needs. For example, Jemma reported that in year five her son Brad was placed in a class with a teacher who his mother described as "old school". She reported the teacher did not accept the contribution of Brad's ASD to his classroom behaviour and consequently he was frequently sent out of class. This led to a decrease in his academic participation that year.

"Year 5 came and his year 5 teacher was a man, he's a man who went to, boarded at [school name] when he was a child, went to catholic teaching college, became a teacher and has never taught anywhere apart from [school name] okay and he must be 57 okay and very old school. So he and Brad just clashed like you wouldn't believe and he would, I didn't even know really until after that he would just yell at Brad and that's the worst thing you can do with a child with Asperger's you know and Brad would just start to laugh... so he'd just like implode then... 'get out of my classroom!'" (Jemma).

All of the parents identified that change of school staff impacted on their children's level of participation. A change of classroom teacher could disrupt the established, positive relationship between a teacher and student leading to reduced student participation. This occurred when the new teacher reportedly displayed a lack of understanding of ASD and was unwilling to modify the curriculum to meet the individual student's learning needs. This disruption occurred both during temporary changes such as a substitute teacher, and permanent changes such as yearly changes of teacher. The following excerpt from Anna describes a change of teacher:

“Grade two- that was his first big change from a person that he adored and who understood him to someone that worked within the system and just wasn’t, wasn’t passionate enough about ASD kids to understand them and research it” (Anna).

On the other hand, where there was not an already established, positive relationship, a change of teacher could lead to the formulation of more positive relationship, thus increasing student participation, as was the case for Declan.

“Last year Declan had a maths teacher who was a very old man and he really should have retired and he was, you know Declan just did not get on with this man and he was quite yeah, but then he went off for a while and the substitute teacher came and once again, but a young teacher, a young girl and she just got them, she got Declan and he performed exceptionally while she was there. As soon as the other teacher came back, good night. So it’s all in the person and their approach and their outlook and I don’t, it’s probably nothing you can train people to be, it’s maybe just in your nature whether you’re good with people with ASD or not” (Hayley).

Hayley’s excerpt highlights the importance of teachers having an understanding of the individual child and the ability relate to people with ASD. In Australia, there has been a focus in recent years on improving teacher training to increase understanding of ASD via the Positive Partnerships Programme (Partnerships between Education and the Autism Community [PEAC], 2013). Interestingly, Hayley perceived the ability to relate to students with ASD was an innate quality rather than something teachers could be trained in.

It was not just the teachers’ approaches that were perceived to impact student participation. Parents reported it was difficult for their children to socially interact with teachers and it took them significant time to adjust to the new social dynamic associated with any change of teacher, as Hayley, Declan’s mother indicated:

“I think it’s because it’s so very hard for them socially to connect with the teachers and once they learn how they can connect with that teacher then to have that teacher taken away and to have to try to have to do it again – it’s almost too much work for them” (Hayley).

This meant reduced time engaged in the curriculum. Anna reported this created a disruption to her son Paul’s participation at the start of every school year. Consequently, from her perspective, it would have been beneficial for Paul to have the same teacher for several years to create continuity:

“It takes him a good first half of the year to get that right, work it all out, work out what he can do and what he can’t get away with and then you might do 6 months of learning or 4 and then it’s back to the same again, do you understand?” (Anna).

“The same teacher for consecutive years would help, even if it was every 2 years they change the teacher at least. Cause I know with Paul it takes him 6 months to work out all the environmental stuff before he can actually focus on learning” (Anna).

A change of teacher was particularly unsettling due to the lack of stability and predictability. Four students experienced multiple changes of teacher within a single school year (the year level at which this occurred was different for each student), which parents described as particularly disruptive to their children’s classroom participation at that time. This was the case regardless of the year that it occurred. In the following excerpt Laura describes her son Luke’s experience in year eight:

“Five English teachers in one term, just no stability and they really need that stability... the routine – he didn’t have any of that, it was just too all over the place” (Laura).

It is perhaps unsurprising that the students found the frequent changes to be disruptive to their participation regardless of age. Insistence on sameness and behavioural inflexibility as well as extreme distress at small changes and difficulties with transitions are core diagnostic features of ASD (APA, 2013).

5.2.2 Sub-theme two: Impact of leadership personnel

Leadership personnel such as the Head of the SEU and school principal also impacted on students’ level of participation according to parents. Four parents reported instances in their children’s educational trajectory where a change of principal led to special needs supports being removed or distributed differently. When changes to models of support did not match the needs of the students with ASD it reduced their participation. Sarah described the changes resulting from a new appointment of a Head of the SEU at her daughter Beth’s primary school in year seven. Although perceived to have an inclusive ideology, Sarah viewed the changes made by the Head had reduced her daughter’s participation in the curriculum as it led to Beth being placed full time in a mainstream classroom without special needs support.

“[The Head of SEU] changed the entire learning support...Kids were split and put in all classes, kids that were used to be permanently special education were put permanently in

[mainstream] classes...we're going to integrate. We're going to be inclusive - for the kids' sake (laughs) which yeah I'm still yet to understand" (Sarah).

In this case there was a mismatch between the Head's' reported interpretation of inclusion – it is only inclusive if the student is fulltime in the mainstream classroom and the parent's perception of inclusion –that the student is able to participate in the curriculum.

Parents perceived that leadership staffs' understanding of ASD also influenced student participation. In the following extract Brendan's mother Mary compares the different approaches of two principals, one who took an interest in ASD and one who reportedly did not believe it existed. The latter removed special education support and enforced disciplinary practices, which decreased Brendan's participation.

"One of them, I can't remember their name, but he took a genuine interest and wanted to know and like wanted us to send the research on Asperger's and how to deal with it, he was really genuinely interested in how to deal with it properly. ...The last one I think whose still there now he was just outright rude!...I don't think he believed in Asperger's at all really. He had no, even though we had the SEP lady working with us at that stage, he didn't want to give any, you know she even said she recommended you know what we should do and he just wiped it out, just go away...he didn't compromise at all ...So it was just 'no you're out of here [suspended] for the week and that's it'" (Mary).

These examples indicate that parents perceive that principals' attitudes towards the inclusion of students with ASD influence their practices in mainstream schools and the subsequent participation of the students. Moreover, they highlight the need for principal education to ensure they have ASD-friendly attitudes. This is consistent with previous research in which parents of children with ASD have reported that principals could positively or negatively influence the inclusion of their children (Humphrey & Lewis, 2008; McDonald, 2010; Penney, 2013), but that effective leadership from the school principal improves students' experiences at school (Humphrey & Lewis, 2008; Penney, 2013).

5.3 THEME THREE: TURNING POINTS

As a whole, parents' reports also clearly showed how their children's participation was characterised by 'turning points', but also the variability of these in terms of impacts on

participation. A turning point refers to a key event that significantly altered student participation either positively or negatively. There were two key events identified by parents: the transition to secondary school (sub-theme one), which for most led to decreased participation; and attending an ASD-specific placement (sub-theme two), which for most led to increased participation. Although these events significantly altered student participation either positively or negatively, they did not necessarily lead to a lasting shift in their participation trajectories.

Sub-theme one: Transition from primary to secondary school

The transition from primary to secondary school was key event that led to decreased participation for most students. All parents commented on the differences between the structure and culture of primary and secondary schools. Notably, there was a perceived mismatch between the expectations in secondary schools and students adaptive functioning skills. Where accommodations were not made to address this there was a decline in students' academic participation. In three cases this led to a crisis point where parents removed their children from the school, one student was then home schooled and two changed schools.

Half of the parents stated that their children did not have the requisite skills to cope with the expectations in secondary schools to be independent and organised as is illustrated in the following extract from Laura, Luke's mother:

"I mean they're looked after in primary school I think still, you know they're cared for whereas once you get into high school you're on your own. You've got to organise yourself, you've got to get yourself from room to room...and you've got to be responsible for yourself and that's not his finest attribute" (Laura).

The transition to secondary school was challenging for many reasons, one of which being the multiple transitions during the secondary school day. The majority of students found the transition from class-to-class difficult. Parents commented that their children's poor organisational skills contributed to difficulties transitioning between classes. Sarah reported that her daughter missed most of her classes due to her organisational difficulties. This meant Beth's exposure and participation in the curriculum was limited.

"Big problem just getting her to the classes, her trying to work out what class she has when – she couldn't follow a timetable, where was she supposed to be? She would arrive at her classes, although it was a great victory for her to find the class, she'd forgotten all her

utensils so then they'd send her back to her locker, but the time she got to class the class was almost over" (Sarah).

Rather than facilitating Beth's participation by making an accommodation such as allowing Beth to carry her school bag to each class Sarah reported that the school were inflexible: "they wouldn't let her – against school rules". Sarah perceived that this simple accommodation would have significantly improved Beth's participation.

"That would have made a massive difference for her because she would have had everything there so at least when they started she could hear the instructions" (Sarah).

Changes from class to class were particularly difficult if the school campus was very large as it was more difficult for students to navigate. Parents reported that students could become easily distracted during the change and took a long time to get to their next class which led to them being late and missing part of class. They were also challenging if there were unexpected room changes as students may not adjust to the change in routine as Hayley described:

"He'd constantly be getting lost...the size issue and the other thing that is a real issue at high school is when they do room changes... I think the teachers are supposed to read the daily notices or the kids are and then they've got to remember that in period 3 the room has changed from what they normally go to, to somewhere else and Declan is never doing that because he just goes to the room that he's supposed to go to (laughs) yeah and then he gets into trouble because he's not at the right room" (Hayley).

Two parents reported that schools recognised their children's difficulties changing from class to class and accommodated this by providing a teacher aide to support the students during these transitions. This enabled them to arrive to their classes on time and to participate for the full length of the lessons.

Transition difficulties were compounded due to the number of different teachers in a single day that had different classroom rules, expectations and pedagogical approaches. This was difficult for students to continually adjust to. This is illustrated in the comment below from Hayley:

"...Because you have so many different teachers [in high school] you have five different approaches to handling one child, whereas in primary school you know you have one approach and you'll be stuck with that for a year if it's no good, but you know you've got

five approaches and the students, particularly kids with Asperger's you know have to get used to those five different people and that's pretty big because they don't really like to have to deal with lots of people" (Hayley).

Another aspect of the transition to secondary school that was challenging was the change in social relationships. For most students this resulted in their social participation becoming more restricted in high school. All parents indicated that their children found it difficult to cope with the increasingly complex social demands of high school. Parents perceived that their children's social differences became more noticeable in high school and that their peers were less accepting of them as Sue reported:

"Especially in the high school I think more so than primary because primary, younger kids are more accepting of anything cause there's not a great understanding of what can happen in life and the differences in people and so on you know, but once they hit high school they're in that puberty age, that teenage age. It's like they distinguish the different races, colours, languages, everything you know and the oddness in someone you know it's all picked out" (Sue).

Parents perceived that their children found it difficult to manage the negative reactions of their peers to their differences. For instance Julia reported that her son Jake made statements to her such as: "I don't fit in, why am I different? Why do I have this? Why do I have to have this?" Three parents reported that their children had attempted to mask their developmental differences when at secondary school. They reported on the high emotional cost of trying to mimic peers, as illustrated in the following extract from Sarah:

"She tries very hard to mimic adolescents when she's with other adolescents and for the first while they don't notice but doesn't take long before they pick it up... and I think that's why so much stress at school because she had to be able to mimic for 6 hours a days straight, that's got to be hard you know" (Sarah).

During this stage of life adolescents begin to make social comparisons between themselves and their peers, and focus on fitting in socially (Peterson, 2010). Carrington and Graham (2001) coined the term 'masquerading' to describe the normal façade that students with ASD adopt to mask their deficits at school in order to fit in with mainstream peers. Similar to the findings in the current study, in their two qualitative studies of the lived experiences of students with Asperger's syndrome

in Australia they found that students engaged in masquerading and this was a significant source of stress for the students (Carrington & Graham, 2001; Carrington et al., 2003).

The findings suggest that students' social participation is so strongly shaped by the dominant peer culture in secondary school that some students resort to desperate measures such as mimicking in an attempt to fit in. This had serious consequences for students' wellbeing. For example, year eight was a crisis year for Beth due to her social issues. Sarah recalled a particular incident during that year when Beth had stolen money from her to pay her school peers to be her friends.

"By stealing that money she was saying I'm so desperate for relationships that I would break the law to get it, 'cause she knows the law and she's a legal person, she's Asperger's. So that for me was a massive turning point because that's how lonely and how desperate she was that she would do that, that's a big deal" (Sarah).

This excerpt indicates that Beth was willing to compromise her identity as a "legal person" in an attempt to fit in with her peers. This incident led Sarah to remove Beth from the school and to begin to home school her. Changing to home schooling was a turning point for Beth, as it positively altered her educational trajectory. Sarah reported that since commencing home schooling Beth had been engaged with the curriculum and was performing well academically.

"The expectation is that she does 15 of these [curriculum] books every term. She is easily getting around 24 done because she's working at her own pace and she has, she got her report last term – straight A's in all subjects [at her current level for each subject]" (Sarah).

Sarah attributed this success to the flexible nature of home schooling, which could be adapted to suit Beth's individual needs:

"She can do it as fast or slow as she wants but she can do it in her pyjamas if that's what she's comfortable in that day...It's totally flexible, works around her completely and I work around her completely you know to get it done" (Sarah).

Not all students struggled with the transition to secondary school; two parents reported that their children had made a good transition, due to several factors. Both Declan and Brendan had a structured transition program from their high schools and were simultaneously attending an AQ placement part-time. Brendan's father described the transition program Brendan participated in leading up to secondary school:

“They call it the [name of program] and it’s for basically the SEP [Special Education Program] kids and [name of transition day] is the day that all the kids go and visit [name of school] but prior to [name of transition day] they actually arrange 3 or 4 other visits so that an aide would take Brendan to [name of school] and he would have an hour or two at [name of school] and that went on for 3 or 4 weeks before [name of transition day]. So he already had some exposure to the school and happily went along” (Glen).

Year eight was a turning point for Brendan. He had previously had a disrupted pattern of participation in primary school; however his mother Mary reported that since beginning secondary school Brendan’s participation had improved. She attributed his success in year eight to a combination of factors – she said that the secondary school staff made him “feel welcome and relaxed” and made accommodations such as reducing the workload and he had made a friend at school. He was also attending an AQ placement part time and was reportedly coming home from there “happy every day”. The following extract indicates the linked lives of Brendan and his family. When Brendan experienced success at secondary school it had a positive impact on the whole family as Mary reported.

“Certainly grade eight and going to AQ, like I said I think this year’s been really good just because he seems so much happier, when he’s happy we’re all happy sort of thing” (Mary).

Two other students - Rhys and Luke, had also participated in a structured transition program at their primary schools leading up to secondary school. Initially it appeared that they too were successfully transitioning into secondary school, however, by the second term of year eight their parents reported that they were having difficulty participating socially at school. In both cases the students found the social demands of high school to be overwhelming and were experiencing bullying during the transition between classes and during the breaks. Luke’s mother reported on a lack of supervision and support from the school to address these issues:

“I think the second term in [name of school] where it really just went downhill badly and fast ... a lot of issues [were] going on in that in-between class time and even in classes a lot of things happened where you’d sort of say ‘well where was the teacher?’ ‘Didn’t you have a teacher aide in this class Luke?’ So I don’t think he was getting his teacher aides, a lot of the time they weren’t there. And then he was getting the bus as well so he got belted up a few times on the bus ... he was getting to the point where he was really upset about being bullied and they were doing nothing about it” (Laura).

Year eight was a crisis year for Luke as his social and academic participation declined significantly. This led his mother to remove him from the school and to enroll him in a different mainstream state school in year nine. This became a turning point as his academic participation increased:

“Academically I think he's done more this year than he has his whole school life. I think he's achieved a lot more and I mean just look at his books, he's not coming back at the end of the year with 2 pages in a book, he's onto his like 3rd maths book or something, I'm not used to this” (Laura).

Luke also began attending an ASD-specific placement at AQ part time and his mother reported that he “loved AQ”. At his mainstream school he had a case manager who advocated for him within the school, maintained contact with AQ and was proactive in making accommodations for him in the mainstream classroom as is illustrated below:

“As soon as there was a problem with Science they put the teacher aide in with him for every science lesson so I mean you can't ask for more than that ...they were all over it. So I think they've been amazing, they've just they've given him what he needs I think. They've given him that support and that back up... [School name] just take on everything that AQ says you know. If [AQ teacher's name] has a suggestion they're like ‘yep, all over it, done’” (Laura).

Luke’s experience highlights that it is not a single factor that enables participation, but rather a combination.

Sub-theme two: Attending an ASD-specific placement

Eight of the nine students in this study attended an ASD-specific placement at AQ some point during their primary or secondary schooling. Parents commonly reported that their children experienced increased participation during this time as most fully participated academically and socially and they experienced a sense of belonging. This was perceived to be a turning point as their participation improved, often for the first time in their educational trajectories, as Hayley noted:

“AQ would have to be one of the good things. That was always, that was the best thing that ever happened to Declan. I think he that he felt comfortable there you know, I think that he felt he belonged there and that he knew that the people there knew about him and his condition” (Hayley).

All but one student experienced increased academic participation at AQ. The increase appeared to be due to the individualised approach that matched each student's unique needs as indicated by Julia:

"They understand his needs, they understood that they are visual, understood their little quirks that they might have and that sort of stuff. Because the classes are small, they usually only have about 6 kids to a class, they get to know each child and their little quirks and that sort of stuff and they work with it" (Julia).

For the student whose academic participation did not increase, her parent Sarah perceived that this was the result of a limited focus on academics at AQ and the fact that academic tasks were not targeted at her daughter's level:

"She missed two years of school; there was no academic work whatsoever. I mean AQ did one session a week with the academic work, but that was definitely directed at the level of say [child's name] and that sort of thing – so the II [Intellectually Impaired] kids...like the ones that were really struggling... there was never any work directed at Beth's level"
(Sarah).

Despite Sarah's critique of AQ she still perceived that there had been an improvement in her daughter's participation there as it was the only setting in which she experienced a sense of belonging. Consequently, she perceived AQ would be the best placement option for her daughter if it could be permanent, and academically appropriate:

"The only place she ever belonged was AQ, but again it didn't provide what it should have been providing, now that's not AQ's fault, 3 days a week, 2 year contract. AQ needs to be, if you want to look at inclusive education - a place where people with Asperger's belong, that is inclusive okay, you need an AQ which is run by academic teachers with all of those provisions in there okay, but it needs to be fulltime and it needs to be for good. You know there needs to be that option" (Sarah).

Parents reported that attending AQ concurrently with mainstream school helped maintain their children's attendance and participation in mainstream school during this time. They reported that AQ staff collaborated with mainstream teachers and provided them with specialist advice and resources, which facilitated student's participation in the mainstream curriculum. For instance Laura reported that AQ was: "really instrumental in the support for the school and in keeping the communication open". Parents also commented that AQ teachers assisted their children with their

mainstream schoolwork on days when they attended AQ. On the other hand, students missed mainstream academic work when attending AQ as Laura described:

"He's getting his homework done there as well so he's got the support there to do that, but he's missing out on two days of school essentially so he's probably falling further behind, but at the same time keeping up a bit better" (Laura).

Four of the students were attending AQ at the time of their interview and were having a positive participation experience there according to parents' reports. However, their parents feared that, without the additional support of AQ, their children would not be able to successfully participate in the mainstream on a fulltime basis, particularly in senior school where academic demands increase. Glen worried that his son Brendan will have missed core mainstream curriculum content while attending AQ part time for two years and might be behind academically:

"My big concern and I think I've said this a few times already is when he leaves Autism Queensland and goes five days a week, and that's going to happen in grade 10 and as we know grade 10 is sort of a fairly big year because it's the transition year into senior. So even though the work isn't so much the same, by the end of the year they're trying to get the kids to have a different expectation of what they're going to do in senior. And it worries me that he's going to go from two days a week to five days a week in grade 10 and even though he's going to pick his subjects in grade nine he may not have had a full exposure for that grade nine year which means when he gets to grade 10 he may be behind scholastically..." (Glen).

Laura feared that her son Luke would not successfully complete school in a mainstream setting:

"It's a real worry if he doesn't have the support of AQ. I mean everyone at school is fantastic but those two days at AQ is just, it gets him through the week I think and if he doesn't have that I don't know how we could do year 11 and 12. He'd just need I don't know maybe to come out of school and do it privately with a private tutor or I don't know. I just don't see how it would be possible" (Laura).

The other four students who had already left AQ at the time of interview experienced disrupted participation upon return to full time mainstream schooling. Two of these students (Jake and Declan) had accessed a second AQ placement during their schooling. Julia, Jake's mother, described the temporary nature of AQ and the reason she accessed a second AQ placement for her son in high school:

“That was grade five to grade six he did that [AQ] ‘cause it was only a temporary placement at the time that she could get him into. And then when we started having trouble again with high school ...[name of AQ principal] took him back again and said that they could help but this is his last time that he can go there. So yeah we’ve exhausted all our time” (Julia).

Three students, including Jake, later exited from mainstream school altogether prior to completing year 12. This indicates that attending AQ offered only temporary reprieve as students’ educational participation trajectories resumed their course after their placement at AQ finished. It did not produce a lasting change to these students’ educational participation trajectories in terms of maintaining their enrolment and participation in mainstream school. ASD is a lifelong condition that requires ongoing accommodations to be made to enable participation in mainstream school. These students returned to mainstream environments that reportedly did not make accommodations to cater for their needs and therefore their participation declined once again.

5.3 CHAPTER SUMMARY

This chapter has presented parents’ perceptions of their children’s participation in mainstream school, taking account of the whole of school experience. The first theme was ‘restricted participation’ which encompassed students’ social and academic participation in school. These findings mirror the broader literature on the participation of students with disability which has reported that they experience restricted participation both at school and has emphasised the environment as having a significant impact on this restricted participation (Coster et al., 2012). The results of the current study in relation to their social participation highlight that their participation was influenced by both school factors, such as their practices in relation to extra-curricular activities and student factors, such as their social skills. Therefore in order to improve students’ social participation in mainstream schools changes to both school practices and support for students are required, such as through the provision of social skills training programs.

The results in relation to their academic participation highlight the inflexibility of the mainstream schooling system in terms of eligibility for learning support and management of behaviour. They also suggest there was a lack of acceptance of difference and a focus on normalisation in mainstream schools and that the need to follow departmental policy was prioritised above accommodating individual students. One explanation could be that their non-conformity affected

the smooth running of the school system and therefore they had to be removed (Blyth & Milner, 1994). In his book ‘People Processing’ Prottas (1979) argued:

Bureaucracies cannot deal with the complexities and ambiguities that go into a complete human being, rather they must categorise a person in terms of a limited subset of attributes or characteristics. Only in this way can a person be sufficiently simplified to be processed by a bureaucracy. (p. 85)

It could be that the complexities of students with ASD and their parents could not be simplified and managed by mainstream schools and so they were excluded.

Parents perceived their children were unable to adapt to the one-size-fits-all model as their disability makes it difficult for them to be flexible (APA, 2013). In light of this they perceived that the onus was on mainstream schools to make the adaptations, but that rarely happened. There was evidence in most cases of inadequate provision as the educational and social needs of the students were not met. In previous studies on the schooling experiences of students with ASD parents have also reported the perception of inadequate provision (Barnard et al., 2000; Batten et al., 2006; McDonald, 2010; Reid, 2012).

The second theme ‘variable impact of school staff’ demonstrated the important influence of school staff, both teachers and principals on the participation of students with ASD. This confirms the findings of several previous studies from the perspective of parents of children with ASD (Humphrey & Lewis, 2008; McDonald, 2010; Penney, 2013). The current study adds an understanding of how changes of staff either increased or decreased the academic participation of the students depending on the staff members approach. Over the course of their schooling students encounter many changes of school staff and there is a need to ensure consistency across these staff in terms of their approach if students are able to continue participating. Additionally, parents reported that their children were particularly sensitive to the change of teacher, regardless of whether or not the teacher had an inclusive approach. One parent suggested the need for less frequent changes of teacher in mainstream schools. However, the implementation of such an approach would require flexibility on the part of schools and willingness to relinquish preoccupation with conformity in the schooling system.

The third theme ‘turning points’ referred to key events that significantly altered student participation either positively or negatively, but did not necessarily lead to lasting change in their

participation trajectories. The ‘turning points’ identified by parents were qualitatively different those described by life course theorists Wheaton and Gotlib (1997) who state that they involve a lasting shift (either positive or negative) in the direction of a life course trajectory. However, parents defined them as ‘turning points’ as they represented points of significant change in their children’s participation. The two events were: the transition from primary to secondary school and attending an ASD-specific placement. The transition from primary to secondary school was a point at which most students were perceived to have experienced reduced participation. It was perceived to be particularly difficult for students due to the multiple changes that take place in secondary school environments and the complex social demands. This transition has been previously acknowledged to be especially problematic for students with ASD (Adreon & Stella, 2001; Dillon & Underwood, 2012). There is a need to prepare students for transitions and to provide individual, tailor-made transition supports (Dillon & Underwood, 2012; Stoner et al., 2007).

There were instances of successful transition for some students in this study when they were well prepared for forthcoming changes. For example, Brendan participated in a structured transition program that included visiting his high school prior to commencing to familiarise himself with the campus and his teachers which prepared him for his transition to high school. This confirms the benefits of preparation in facilitating a smooth transition for these students. Having access to an ASD-specific placement at AQ at the same time assisted the students during their transition to high school. AQ staff provided professional advice and resources such as visual schedules to the mainstream school during this period and facilitated communication between home and school.

Attending an ASD-specific placement at AQ was perceived to be another key event and it led to increased participation within that environment for most students. In particular, parents indicated that their children found a sense of belonging in the ASD-specific environment. These results challenge the dominant perception that inclusion can only occur in a mainstream environment. It highlights that for these parents inclusion was not connected to a place, but rather about meeting the needs of their individual children and enabling them to feel a sense of belonging. Although positive, there were issues with integrating the AQ program with the mainstream curriculum, which at times impeded academic progress for students. Furthermore, the AQ placement was temporary and once students returned to mainstream school full time their social and academic participation declined. This indicates that their participation was particular to the AQ context and suggests that some students may need ongoing placement in ASD-specific schools, as they may not be able to participate successfully in mainstream schools if changes are not made to accommodate them in these environments. Several previous studies on the mainstream education of students with ASD

have reach similar conclusions and have recommended that because of the heterogeneity of students with ASD a range of educational options should be provided including ASD-specific schools to ensure they have access to an education that meets their unique needs (Batten et al., 2006; McDonald, 2010; Reid, 2011).

This chapter has explored how parents perceived and made sense of their children's participation in mainstream school over time. It has developed an understanding of students' restricted participation over time and identified that this was perceived to be the result of a mismatch between the students and their school environments. It has also highlighted the potential for changes in participation resulting from changes in school staff and changes of school. The next chapter will build on these results by describing and analysing the participation trajectories of the students with ASD.

CHAPTER SIX: THE PARTICIPATION TRAJECTORIES OF STUDENTS WITH ASD

This chapter addresses the research question: what are the participation trajectories of students with ASD in mainstream schools? The analysis is based on parent data with a focus on understanding students' patterns of participation in mainstream school taking into account the whole experience from commencement to time of interview. As reported in the methodology chapter, the participation trajectories for the students were mapped on trajectory grids for the period from birth through to high school thus far (Appendix 11). At the time of their interviews (late 2011/ early 2012) students' year levels ranged from year eight to year 11. Their trajectories were therefore mapped to different end points. During analysis common and divergent patterns of educational participation were examined across the students in relation to their attendance, enrolment and social and academic participation over time.

Concepts from Life Course Theory (Elder & Giele, 2009) were used to develop the analysis of student trajectories including: transitions, turning points and cumulative influences. Transitions are changes of role or statuses that are embedded within a trajectory (Elder & Giele, 2009). A turning point is a special life event that produces a lasting shift (either positive or negative) and significantly alters the direction of a trajectory (Wheaton & Gotlib, 1997). During the interviews, parents were asked to identify turning points in their children's educational trajectories. Other turning points were identified through examination of the data. Parents' perceptions of the influence of students' early experiences of participation on their later experiences were explored to determine whether there were perceived cumulative influences on their children's participation trajectories.

This chapter begins by describing students' participation trajectory types. Then, two students' educational journeys are provided to illustrate the trajectory types. The chapter concludes with a discussion of the findings with reference to the literature.

6.1 PARTCIPATION TRAJECTORIES

Notably, over half of the students had been discouraged from enrolment in at least one mainstream school over the course of their schooling and some at multiple schools. Further, parents reported that lack of funding was given as to the reason why their children could not be included. Parents were not directly rejected but perceived that they were forced not to pursue enrolment due to the lack of resources to support participation. Consistent with Kearny's (2009, p. 204) argument: "it

may not be the actual levels of funding that are the barrier to disabled students presence and participation at school, but rather the belief that a perceived lack of funding is a legitimate reason to exclude disabled students”.

The analysis of parents’ reports of their children’s participation as a whole showed two types of participation trajectories: namely ‘disrupted participation’ and ‘relatively stable academic participation’. While the students grouped within a particular type of trajectory shared some commonalities in terms of the pattern of mainstream participation, there was still considerable diversity in their experiences. To contextualise the presentation of the two representative student participation trajectories, this chapter begins with a brief descriptive overview of the two trajectory types elicited through the analysis.

6.1.1 Disrupted participation trajectory

Seven students schooling experiences as a whole, as reported by parents, were consistent with a disrupted participation trajectory: Beth, Claire, Paul, Jake, Luke, Declan and Brendan. There were many sources of disruption and exclusion for these students including: (a) exclusion from the classroom and the curriculum (e.g., frequently spending time outside the classroom with limited time spent engaged in the curriculum; (b) exclusion from the playground (e.g., being required to spend lunch times in special education units instead of being in the playground with friends; (c) exclusion from school (e.g., restricted hours of attendance at school with parents regularly being requested to collect their children before finishing time; repeatedly being suspended from school; and (d) exclusion from school activities (e.g., being excluded from participating in school camps, concerts and sports days).

Disruptions were frequent which meant that individuals had restricted participation at school for most of their schooling years. As a result of these exclusionary practices, four of the parents repeatedly resorted to changing schools in search of a more inclusive school placement. The other three did not do so as they perceived a change of school would be a further disruption to their children’s participation. While all of the students predominantly had experienced restricted participation, they all had enjoyed some periods of positive participation at some point during their schooling when schools accommodated their individual needs better than at other times.

At the time of their interviews, student trajectories diverged. Beth, Jake and Paul had left mainstream schooling altogether and instead were either home schooling (Beth and Jake) or in a supported work placement (Paul). The other four students were still attending mainstream schools.

Brendan and Luke were attending new mainstream schools part time and an AQ school part time and were experiencing successful participation in both settings. As described in the previous chapter their parents remarked that this was a turning point for their children. Claire remained in the same mainstream school and continued to experience restricted participation. Her father was considering removing her from the school to do home schooling. Finally, Declan changed mainstream schools and found a school that was welcoming and accommodated his needs. This change was a turning point for him as it produced a lasting shift in his educational trajectory. He went on to complete year 12 and obtained his high school certificate. He is currently participating in a full time traineeship. His experience indicates that trajectories are not entirely predetermined by early experiences, but rather there is potential for positive change, even later in an educational trajectory. This finding supports a key assumption of life course theory - that there is potential for change across the life course (O’Rand, 2009).

According to Life Course Theory, “early events can have lasting consequences by affecting subsequent transitions” and can set in motion “cumulating advantages and disadvantages” (Elder, 1998, p. 7). When these cumulative processes occur they can be either path-dependent (e.g. the inequality continues over time) or reversible (O’Rand, 2009). This study explored the way that students’ early experiences of disrupted participation may have shaped their later experiences and whether there were cumulative influences on their participation trajectories. Four parents whose children were part of the disrupted trajectory group perceived that early experiences at school shaped their children’s perceptions and responses in mainstream schools over the course of their schooling. Early disruptions to participation led to a lasting negative impression of school and maladaptive responses to school. For example, Philip reported that his daughter’s negative first impression of school discouraged her from engaging in school from that time onwards.

“The first impression kids get of school is the impression that sticks for life and hers was rotten straight away, so it put up a barrier” (Philip).

Negative early experiences in primary school were perceived to have led to entrenched, maladaptive behaviour patterns in the students, including avoidance and school refusal that continue to this day. For instance, Hayley observed of her son Declan:

“Well I guess he learnt some behaviours and some coping skills in primary school that he uses today and that is if you play up enough you’ll be withdrawn from class, if you get withdrawn from class you don’t have to do any work, if you don’t have to do any work then there’s no pressure on you, yeah and he uses that today... he also has learnt if you play up

enough you'll get suspended and then that means you stay at home and that's great cause he doesn't really want to go to school anyway" (Hayley).

This behaviour management strategy used early in Declan's schooling therefore inadvertently reinforced his maladaptive behaviours and reduced his participation.

Extended exposure to unfavourable participation conditions (e.g. restricted participation) appeared to have a cumulative influence on academic achievement for some of the students. Half of them were behind academically at the time of their interviews. Their parents reported that there was a gap between their children's actual numeracy and literacy levels and levels expected for their school year. For example, Beth was in year nine, however in different subjects she was performing well below her year level:

"...Her English is grade six level, her maths is grade seven level, her spelling is grade eight level, and her science and SOSE are grade seven level" (Sarah).

Parents were concerned that their children would not complete high school or go on to higher education. They felt that without a high school qualification their children may be restricted to lower paid employment as illustrated by Anna:

"He's going to end up in that lower socio-economic bracket which is rife with crime; it's not a great outcome" (Anna).

Initial inequalities in education may be magnified over the life course leading to cumulating disadvantage (Pallas, 2002). Prior research with young adults with ASD who had poor experiences at school revealed a range of negative, long-term outcomes including: (a) enduring mental health problems (Portaway & Johnson, 2003), (b) a need for support in adult education for issues of comprehension, (c) organisation and managing academic workload, and (d) poor job prospects and unemployment and social isolation (Autism Spectrum Australia, 2012). Thus, there is a need to optimise social, behavioural and academic success for students with ASD from the start of their schooling so that they have the same opportunities as typically developing students to complete school and lead a fulfilling adult life. As one parent in this study indicated:

"That's the blueprint isn't it and that's why it is so important, those early years they have to get it right, they haven't got 10 years to waste trying to get it right. They need to have it running, hit the floor running with these kids" (Anna).

6.1.2 Relatively stable academic participation trajectory

The educational experiences of the remaining two students showed a more stable academic participation trajectory across the school years as a whole, including stable attendance at mainstream schools and relatively few changes of school. The two students with experiences that were considered to fit this trajectory were Brad and Rhys. Based on their parents' reports, they consistently engaged with the curriculum throughout their schooling. For example, Jemma, Brad's mother said: "I think he can participate in everything academically". In both cases their parents reported that their schools made modifications to academic tasks to support their participation. Despite this more positive picture, they also frequently had difficulty participating socially and their social difficulties increased once they entered high school. For instance, Jemma commented:

"Now he's at high school they do a lot of group assignments and things like that and there's been one or two that's he's had to do by himself because he hasn't got anybody to do it with" (Jemma).

Both students experienced one school year that was disrupted but the timing and cause of this disruption differed. In Brad's case the disruption occurred in year five when he was placed in a class with a teacher who his mother described as "old school". She reported the teacher did not accept the contribution of Brad's ASD to his classroom behaviour and consequently he was frequently sent out of class. This led to a decrease in his academic participation that year. The disruption to Rhys's participation occurred in year eight. The circumstances surrounding this disruption will be explored later in the chapter when his participation story is presented. At the time of their interviews, Brad was attending year eight fulltime in a catholic school. Rhys was attending year nine in a state school part time and AQ part time.

This study explored the way that students' early experiences of stable academic participation may have shaped their later experiences and whether there were cumulative influences on their participation trajectories. Unlike most of the parents in the disrupted trajectory group, the parents of the students in this group did not report that their children's early experiences of participation had shaped their later experiences. However, it could be interpreted that these students experienced cumulative advantage in relation to their academic participation. They had extended exposure to favourable academic participation conditions, for example their parents reported that academic accommodations were made throughout their schooling to support their participation as illustrated by Jemma: "he did get learning support in class and he had learning support all the way through".

The students consistently performed well academically across their schooling and their parents were optimistic about their potential to finish school and to further their education at university.

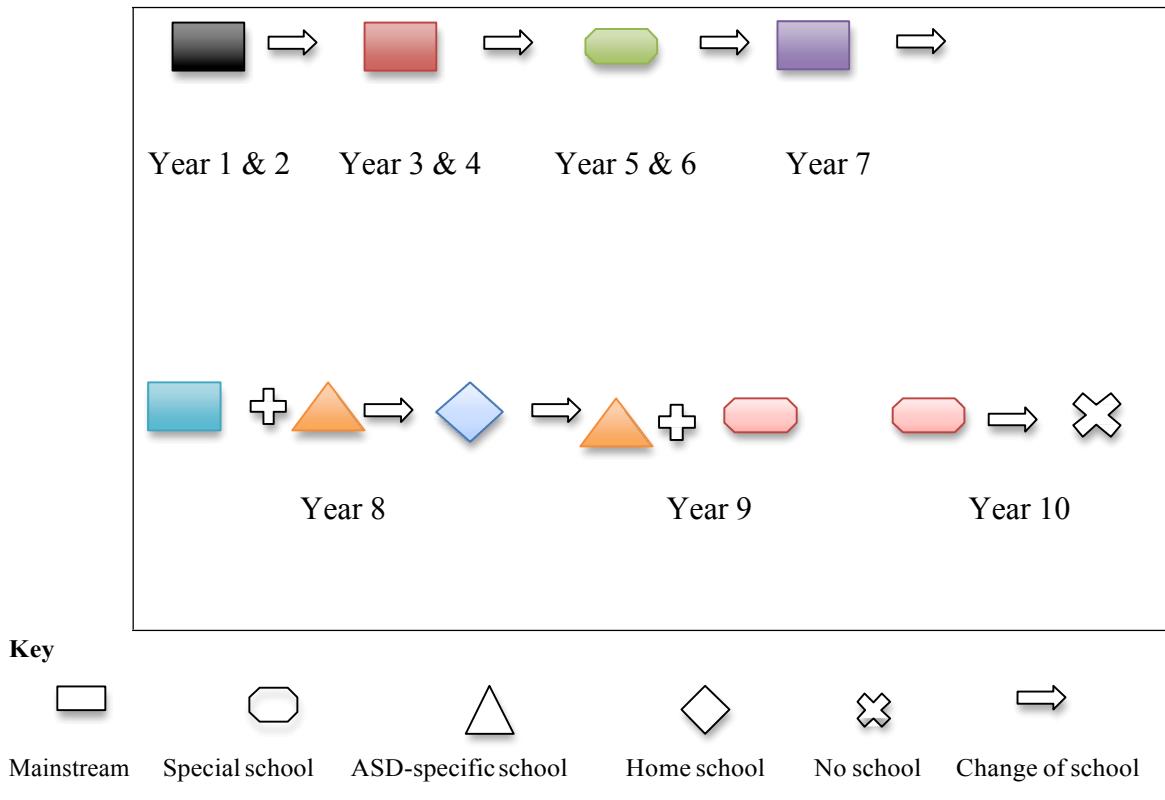
Good academic performance and parent expectations of participation in postsecondary education have been found to be significant predictors of participation in postsecondary education for students with ASD (Chiang, Cheung, Hickson, Xiang and Tsai, 2011). However, even if the two students in the current study (Brad & Rhys) do go onto university it cannot be assumed that they will continue to experience academic participation in that setting since there is potential for continuity or change in trajectories over the life course (O’Rand, 2009). Furthermore, there is some research to suggest there are barriers to participation in higher education institutions for young people with Asperger’s syndrome. Madriaga & Goodley (2010) conducted life history interviews with eight students with Asperger’s syndrome in their first year of university in the United Kingdom and found that the students experienced barriers to participation within lectures, group work and assessment leading to an experience of marginalisation. However, this is a small-scale study in another context so it is not known if students with Asperger’s syndrome in Australian universities are experiencing similar barriers.

6.2 STUDENT EXAMPLES OF TRAJECTORY TYPES

Two students’ participation as a whole across the schooling years are presented below to illustrate the two trajectory types. The student representative of the disrupted trajectory group is presented first. Paul’s participation example was chosen as it best illustrates the numerous disruptions experienced by students in this group and the detrimental consequences of these disruptions to his educational participation. It also highlights the challenges of students with complex conditions due to multiple co-morbidities e.g. cerebral palsy, epilepsy and borderline IQ. It identifies the periods in which he was able to participate and identifies the factors that facilitated this. The story was written based on the reports of his mother. Figure 6.1 provides a visual representation of Paul’s trajectory and indicates the large number of schools he attended.

Figure 6.1: Visual representation of Paul's trajectory

(Figure adapted from O'Connor, 2012)



6.2.1 Paul's Trajectory

Paul, the fourth child of Anna and Tom, was born in 1996 in a small rural town in Queensland. He was diagnosed with epilepsy and cerebral palsy, soon after birth. At two years of age he accessed a Special Education Development Unit (SEDU). At four years of age, his family moved to a neighbouring small town. During this year he was diagnosed with Asperger's syndrome by a pediatrician. He attended a local preschool and Special Education Unit where he received appropriate education that accommodated his special needs.

“They were really good at the preschool, they were right on top of it which was great, they were working with the special unit that used to come over and do all their assessments and Paul would go over there to do their sensory programs at the special unit”.

During this time Anna and Tom's marriage was described as “falling apart” and they later divorced. When year one approached Anna and her four sons were still living in a small town and the school options in the local area were limited. She attempted to enroll Paul in year one at the local private

school that his three older brothers were already attending but was informed that this was not possible as his educational support needs were too high and the school did not have the resources to support him.

"We had meetings with them and they were very up front that they couldn't cope with Paul ...they just didn't have the staffing, he needed one on one supervision at that time... whether they could have got it I don't know, but that was, I just think it was put in the too hard basket".

Anna then enrolled Paul in the local state school, where he was placed in a special education class. She described his first year of school as a success. As his classroom teacher had previously been an Advisory Visiting Teacher (AVT) for Autism, she was knowledgeable about educational approaches for students with ASD and used a number of strategies that assisted Paul to participate optimally in the classroom fully accessing the curriculum such as visual supports, routines and rewards to motivate him. Paul also had a teacher's aide who reportedly worked well with him using the same strategies. Paul and his peers were attending mainstream class for two hours per day. Paul's early experience of school was positive as he successfully participated in academic tasks in the special education class. In year two, on the principal's direction, Paul and his peers from the special needs unit were integrated into a mainstream class fulltime. The principal's decision appeared to be influenced by an inclusive ideology.

"The principal was wanting the kids to be included in the mainstream classrooms rather than the unit... because it's their right to be included -that was the language that the principal used when I did challenge him with this. 'He has the right to be included' and yes he does, but he also has the right to have an environment that he can cope in and that was the bit that they failed to see".

There was a mismatch between the principal's interpretations of inclusion – it is only inclusive if Paul is fulltime in the mainstream classroom and Anna's perception of inclusion – that Paul is able to cope.

The change of teacher in that year also led to a decline in Paul's participation as the new teacher did not make accommodations for his special needs. It appears that the pedagogy was not adjusted to accommodate Paul's language and cognitive difficulties and this exacerbated his anxiety:

"He would never learn from the blackboard, he would never. He had little or no speech at that time and she [his teacher] wasn't aware he had a 13 second processing delay so she

wouldn't allow time for him to actually respond, to process it and respond in whatever way he could with his card or with some eye contact. She would just continue to banter and throw the instructions at him too quickly and then he would just get anxious and then get really unhappy sitting there and then he would take off".

Anna reported that during this time Paul would run away from class repeatedly each day, which caused frequent disruptions to his classroom participation. The school would then call Anna for assistance and she would be asked to take Paul home. The school then reduced Paul's hours to half days at school. When he was at school Anna reported that he spent most of this time in the 'time out tent' and wouldn't attempt the school work as he was experiencing sensory issues which interfered with his concentration. Consequently Paul's participation in the curriculum and the school environment was disrupted during this time.

"I think he was just trying to block everything out that he couldn't cope with, you know the noise of the other kids, the tapping of pencils, the fan going, things like that, the teacher writing with chalk on the chalk board. I think it would just send him into sensory overdrive and he would retreat to this place in the back corner of the classroom which was farthest away from all the noise and all the hustle and bustle of the classroom".

By this time Anna was working in a larger town 60 kilometers away from home. She and her children moved to the town in which she was working and she enrolled him in a new school there for year three. In the new school Paul's classroom participation remained limited as he continued to regularly leave the classroom. While the school offered him a safe haven, Anna perceived that the room they chose was inappropriate:

"Paul would refuse to stay in the classroom so then he would just roam around. They tried to give him a safe haven to go to - they chose the wrong safe haven. They chose the RTC room -Responsible Thinking Room so then Paul thought that he was always in trouble".

Anna acknowledged that the teachers tried to engage Paul, however they encountered difficulties both due to lack of resources and Paul's behaviour, namely his school avoidance:

"The teachers were under-resourced, over-worked. I got the impression that they were just so snowed under with other kids and Paul was not willing to engage with them at all...they tried to engage him with puzzles and fishing games and things like that but I think at this stage he'd now had a nearly two year lapse in any kind of good schooling and I just think that the evasion and behaviours were there and he learnt how to get home".

Paul attended this school only two hours each day. Hence his participation in the curriculum and the school environment was limited once again. He was placed in the special education unit with a teacher's aide providing one-on-one support. By year five Anna reported that the school wanted to reduce his attendance to one hour each day as the situation "wasn't working for the school". She disagreed with reducing the hours as she said it was the school's responsibility to help him cope and requested a meeting with the district office:

"I asked district office to come in and go 'can we look at doing something better than this?' because it wasn't working for me, it wasn't working for Paul and more importantly it wasn't working for the school. ...That was when they [district office] recommended Paul go into the special school".

Paul then attended a special school for years five and six. Anna perceived that the special school was a better fit for him than the mainstream school due to the smaller class size, increased level of teacher support and practical curriculum, which matched his needs.

"Smaller school, better supervision, they had gates around the school at that time that were high enough that Paul couldn't escape from. And just the one-on-one teaching you know. They have the classes of five, one with a teacher and an aide so the student ratio was better ...the curriculum they did it was hands on. It was interesting but it was also maths and English. They might do their maths and English through cooking classes which also gave them the life skills for later. So rather than sitting them down at a desk saying we're going to do this, they got them in the kitchen, they got them doing the visual learning you know. They would read because they wanted to make the recipe".

Paul attended the school full time, five days each week. Anna described this as a turning point in his educational trajectory as he made significant gains academically as the curriculum matched his language and cognitive skills and he participated socially for the first time as the school enabled him to participate in extra-curricular activities such as sports and school camp:

"He started reading; he went up from level two reading to level 17 in a term. He was interested, he was having successes, feeling better about himself ...he was included, he went to his first party, he went to his first sports day ...he went on school camp, he did all of it. Now that was inclusion. They talk about the right for inclusion, yes, okay they do have the right for inclusion, but they have to be able to cope too. And he was included.... Like for the first time he would walk into the school and he obviously felt he belonged".

Another turning point came when Paul was in year seven. Anna had a serious car accident and sustained a spinal injury. She required four months of inpatient rehabilitation in a metropolitan hospital in Brisbane (four hours south of the family home). During this time Paul and his siblings remained in Bundaberg with family and friends. Following this Anna and her children moved to Brisbane and she continued rehabilitation as an outpatient. She contacted Education Queensland and requested that Paul be transferred to a Brisbane special school. Her request was denied:

“The Senior District Guidance Officer had said ‘no he doesn’t just get a free pass to a special school’ because at that stage he didn’t have the intellectual impairment diagnosed you know. ...His WISC [Wechsler Intelligence Scale for Children] test came in at 72 which is only two above [the cut off for being diagnosed with an Intellectual Impairment]”.

An IQ of 72 is considered borderline and by denying Paul a placement in special school the guidance officer’s demonstrated inflexibility in the application of criteria for special school. This was yet another disruption to Paul’s participation. He then attended a mainstream state school in Brisbane for year seven. Anna described his limited participation in social events and academic tasks during this time:

“He didn’t participate, the sports, he didn’t participate in school discos, he didn’t participate in the graduation all of which he wouldn’t have coped with and he wasn’t even participating in any kinds of work at the end. It was just more doing, they allowed him to do that fish painting that’s what they did. But he would just go to school and work on this fish painting and that was basically what he did for the last term ...he stayed in the unit most of the time, but then also took off a lot and the Principal up there used to just call and say ‘come and get him’”.

It appears that exclusion from the curriculum and social activities reduced Paul’s academic abilities and increased his mental health issues. Anna reported that Paul had developed anxiety and depression and she felt this exacerbated his epilepsy:

“Towards the end of grade seven he had a massive block of seizures brought on by stress which actually gave him an acquired brain injury”.

Anna described the Head of the Special Education Unit as one positive feature of year seven. She said that he was understanding and worked with her including assisting her with an application to get Paul a part time school placement at AQ (he was the former principal there). This illustrates the key role that a school leader played in facilitating Paul’s participation.

Paul attended AQ two days per week. Anna identified AQ as another turning point in Paul's educational trajectory as his social and academic participation improved there. It was also a turning point for Anna as she was included in his educational decision making for the first time and collaborated with the AQ staff. This extract highlights the importance of home-school collaboration to enabling Paul's participation at school.

"It wasn't school and home as a separate thing, everything was combined. Everyone worked on the same behaviours and plans and we took across all aspects of his life. That was fantastic. They brought you into the classroom so you could see how they acted at school and also how the teachers responded to inappropriate things so you were actually brought in as a teaching tool for yourself which was great".

In preparation for Paul's entry into high school Anna contacted a number of private schools, but was discouraged by the school principals from enrolling Paul in any of them:

"I had talked to some private high schools and they couldn't take him with the degree of his behaviours. ... Well they wouldn't refuse him they just said we can't give him what you're saying he requires. They were really upfront with it and in the end I knew it wasn't going to work".

In year eight Paul attended the local state school and continued to attend AQ part-time. Anna reported that the transition meeting that occurred prior to Paul commencing high school did not go well as she perceived that the school had unrealistic expectations and when she voiced her concerns the school did not take her feedback on board:

"We had the interview and the lady said okay this is what's required of Paul, he's required to get himself to and from school, he's required to do eight subjects, to get himself to and from the classes, and my mother and I just sat there and said 'there's no way in the world that he'll do this' ... I did say to them 'whatever you want Paul to do at your school, you need to implement on your transition days because if you're gonna keep it all fun he's gonna think that that's what school is, [what] your school is all about'. They didn't do that".

The school reportedly lacked willingness to make educational adjustments for Paul and consequently, his transition to high school did not go well. Anna reported that Paul could not cope and refused to participate and that the school's response was to restrict his participation further as the year went on.

"He was being sent home, he was lashing out and being locked in rooms, we had classroom evacuations, we had just all these things that Paul wasn't coping. So once again we started reducing the hours. ...At that stage he was going to AQ three times now, three times a week. So it was only two days that they had him. His numeracy, literacy I did at home with him and they took him fishing and did craft with him and cooking. I think they were trying to gain his attention by doing good stuff ... but when they tried to implement any kind of schoolwork he wouldn't do it. And then from there we went down to two hours per day instead of a half day - the school's recommendation. Many meetings with district office and all of that was their recommendation as well. ...then in the end he wasn't even in the classroom or the unit. He did an hour and 10 minutes a day in the manual arts room with two teachers".

Anna then removed Paul from the school and attempted to home school him via Distance Education. She reported this was unsuccessful due to the level of difficulty of the curriculum and Distance Education's unwillingness to adjust the curriculum to accommodate Paul's cognitive level.

"That didn't work either because they couldn't set a program lower than grade five for a high school student. ...it was far too hard for him. ...We asked for simpler stuff, they said they couldn't do that. ...because it was a high school program, he was a high schooler".

Anna requested the involvement of district office once again and after further assessments and evidence provided by Anna they established that Paul was eligible to attend special school.

"They did another WISC test – that came in at about 78 I believe, but I forced them to do an Adaptive Needs [test]. Which he was really low in and then I found some, something just reminded me, something that when he had the CT scan I remembered them saying "we are now looking at dead areas of the brain" and when this woman from district office was saying "he can't go there unless he's I.I. [intellectually impaired]" I thought okay so I pulled out the paperwork... the results and on it [it said] he had cerebral dysfunction and they were the words that needed to be used for special school so then we realised that we've got this document. Okay we don't have to go through this fight anymore and then he got sent to special [school]."

Anna enrolled Paul in a special school for year nine. This was another positive turning point as Anna reported that his social participation improved during this time:

"It worked. He knew he couldn't get away with things there and he had the respect. In the end he wasn't even trying to, he had confidence again, he was having successes and socialising and having a pretty good life".

In year ten Paul continued to attend the special school. Anna reported that Paul's social participation declined. He was being bullied and after one particular incident with his peers he was suspended.

"There was lots of bullying going on, an awful lot of bullying. One day Paul retaliated and pulled out an aerosol can of deodorant and sprayed it at the kids after he'd been saying "go away, go away, go away" and he got suspended for that – using a weapon".

The principal had changed that year and later in the year Paul was suspended again, this time due to an incident with the principal. The change of principal led to reduced participation for Paul as the new principal reportedly had a different ideology to the previous one and changed the practices at the school. Anna reported he did not want Paul at the special school.

"This year has not gone well. ...last year the principal was good. This year we have a new one who came in with his own set of ideas that the kids weren't going to do their numeracy literacy with the hands on stuff they were going to sit in classroom at a desk. ...they had to do an hour and half a day at a desk and everything went terrible. Not just for Paul, for the other kids as well. ...And the principal now believes that Paul shouldn't be at that school because he's too able ...he's applying for an early exit for him from the school to go into a work placement - a proper work placement full time or longer than the one day a week".

At the end of that year Anna reported that Paul was no longer attending the special school. He was participating in a part-time work placement organised by a disability employment support service. Anna expressed her hopes for Paul's future but expressed concerns about his mental health.

"I hope that he finds something that is going to stimulate him, going to want him to learn more, even if it is a focus area. To be happy - that's probably the biggest thing, just whatever he can do it makes him happy; it makes him get out of bed. It doesn't make him go 'life is too hard'. I see that now is my biggest problem is [Paul's] mental health. So we've already started that and there are big concerns".

Paul's story illustrates numerous disruptions to his educational participation trajectory. He attended a number of mainstream schools and from his mothers reports it appears few accommodations were

made to support his needs in these schools. Consequently he spent large portions of time outside of the classroom and out of the school environment altogether. There were several turning points in his educational trajectory. He had periods of positive participation when accessing AQ and the two special schools as these environments provided a better fit for his social and academic needs through appropriate pedagogy, curriculum and peer group. However, these placements were temporary and at the last special school a change of principal, and the changes in school practices that followed, were the catalyst for Paul's exit from the mainstream education system altogether.

Overall Paul's educational participation trajectory was characterised by long periods of restricted participation. This prolonged exposure to restricted participation has produced negative cumulative impacts such as limited comprehension of numeracy and literacy as described by Anna.

"He's had probably out of the whole lot of the 10 years probably only two years of successful schooling, so that stands out and that's where he is at with his literacy and numeracy, they are in keeping with that".

It has also produced entrenched behaviour patterns such as avoidance and a lack of willingness to engage in any further education as illustrated by Anna.

"It's too late for Paul ...he's now 14 and he has the skills of a seven year old. He's now got it in his head that schools aren't doing him any favours, why should he try? He's shut down. I believe he shut down a long time ago".

Paul's story also demonstrates the linked lives of parents and their children. Events in Anna's life such as the car accident impacted on Paul's participation at school. Likewise, Paul's disrupted schooling impacted on Anna's life. Schools repeatedly restricted his hours of attendance and relied on Anna to collect him during the day. Anna engaged in constant advocacy throughout his schooling in an attempt to secure inclusive educational provision for Paul. While her efforts produce short-term changes his participation soon became disrupted once again. Paul had complex needs and based on his mother's reports it appears that for the most part mainstream schools were unable or unwilling to accommodate these needs.

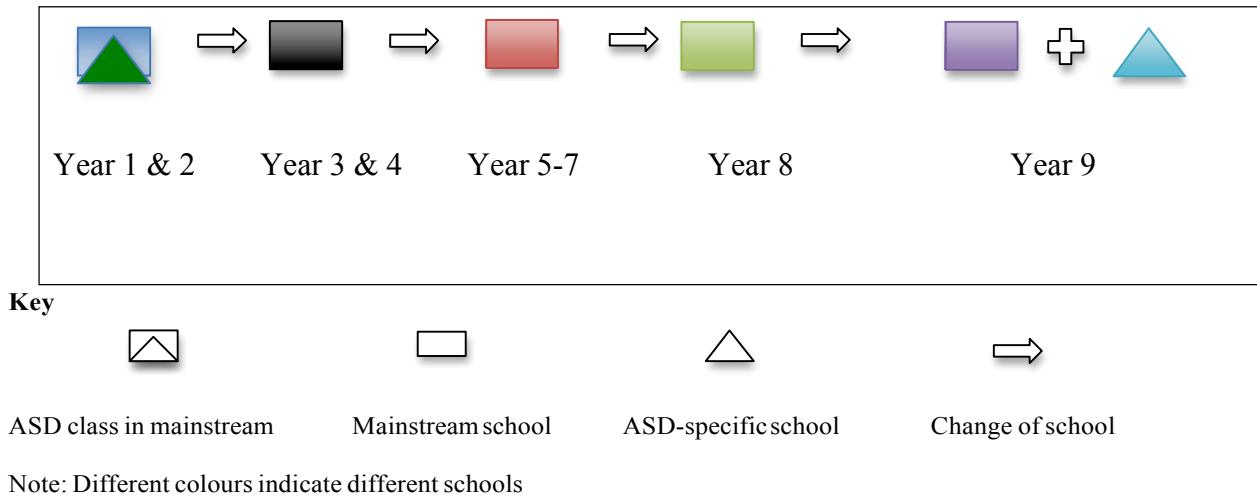
6.2.2 Rhys's Trajectory

The trajectory of one student from the relatively stable trajectory group is presented next. Rhys's trajectory was chosen because it best illustrates the pattern of stable attendance, academic engagement and achievement. It also highlights the social struggles of students in this group and the

loneliness and depression that resulted. The story was written based on the reports of his mother. Figure 6.2 provides a visual representation of Rhys's trajectory.

Figure 6.2: Visual representation of Rhys's trajectory

(Figure adapted from O'Connor, 2012)



Rhys was born in 1996 in Sydney, the third child of Sue and Bryan. Rhys attended kindergarten in Sydney. Sue reported that he had difficulties with social interaction during his year at daycare and was excluded as a result.

"He wouldn't sleep, he just wouldn't stop all day and his interaction with other kids was to just go up and just smash them or just hit them or kick them and stand there and wait for their reaction and got more frustrated when he got the wrong reaction and things like that...they actually asked me not to bring him back".

At age three Rhys was diagnosed with Pervasive Development Disorder - Not Otherwise Specified (PDD-NOS). Following this Sue accessed therapy for him, which included a weekly playgroup with other children with disabilities; and a teacher who conducted home visits once per week.

"He had a teacher for one whole year that used to come out once a week to help him learn shapes, expressions, sad, happy face, the whole thing ...This was to help him prepare for school; this is round three or four Which was great because he had bad sensory [issues], they worked with sensory [issues], socialisation [issues], everything with him".

This program assisted Rhys with the transition to school. At age five Sue enrolled Rhys in a mainstream school with satellite classes specifically for children with autism run by teachers from

the Autistic Association of NSW. He completed his academic lessons in the satellite class but participated socially with his mainstream peers during break times.

"They were just a normal public school, but they had a couple classrooms that they allowed the autistic association [to] come in [and run] ...at lunch time and morning tea they mingled with the mainstream school. If there was things happening in the mainstream school they participated in it except they were in their own classrooms with their own specialised teacher and that was fantastic, they had a bus that used to pick them up at the door, bring them home at the door, and that was to help get that social side".

Sue reported that the staff in the satellite class soon noticed that Rhys was performing well academically and organised for him attend a local mainstream school from year one onwards. In progressing this, a range of transition strategies were put in place for example:

"[The staff] set up a booklet, they set up meetings with the school which was just round the corner, walking distance from where we lived, he got to know and meet his teacher before he actually started the school like the previous year, he got to go up to the school to see the surroundings. They done a booklet for him and took a picture of what classroom and everything else. He was allowed to use the specialised toilet, wheelchair toilet and all that, so it was all set up and it was great".

These transitions supports enabled him to make a smooth transition into mainstream school. In early primary school Rhys remained at this school. Sue reported he had some social difficulties but also had some social success due to the support of a teacher's aide. He was also socially included outside of school.

"He had his own teacher's aide because they had to monitor his behaviour and make him and push him to do his work ...and to interact, so the other kids slowly became aware that oh you know there's something wrong with Rhys sort of thing, but that didn't matter. He got invited to birthday parties and I'd make sure he went to them and meet the other parents and kids come over and he'd go over there so it started all working".

When Rhys was 10 years old he and his family moved to Brisbane. Sue reported that Rhys's transition to the new primary school in Brisbane went well as his new school was well prepared for his arrival.

"His previous school down in Sydney they sent all paperwork up about Rhys and the autistic association so they [the new school] were well aware of everything with Rhys and they were more than willing to participate with Rhys".

The Deputy Principal played a crucial role in supporting Rhys during the remainder of primary school. He had weekly contact with Rhys. When Rhys began to have social difficulties with his peers during break times the Deputy Principal assisted him by providing supervision and this improved Rhys's social relationships.

"The only outlet he sort of had was the deputy principal, he really got attached to him cause he was a down to earth sort of guy... so he started seeing Rhys once a week and talking with Rhys and stuff like that. The first year went pretty good and then the next year things started happening... When it's lunch time and play time in that sort of surroundings mate you make your own rules [for rugby], Rhys wouldn't have it, he just couldn't have it that they made their own rules and they just kicked him off the team. So the Deputy Principal stepped in and thought well Rhys can be Referee so he used to go out there at lunch time and get Rhys but then Rhys was a little bit too harsh so that's why he had to supervise that aspect of it. Yeah it was quite cute actually to keep him in there and for those kids to try and like just give him a go".

The school continued to be proactive in supporting Rhys's social issues. In year six Rhys was placed in a class with familiar peers who understood his condition, which enabled his social participation. Sue reported that Rhys consistently participated academically in the classroom throughout later primary school.

"They decided the following year to pick a few kids that realised how Rhys was, understood Rhys and dealt with it so they were really good they made sure he was in the class with kids that knew him and would socialise with him".

"He was set the work, he would do that work ...he'd finish before just about everybody else you know and they'd give him a book or he was allowed to pass the time until the rest of the kids were finished".

However, he also experienced social issues in the classroom, which according to Sue were due to his lack of awareness of social etiquette. This limited his social participation at this time and impacted his mental health. In year seven a negative turning point occurred - it became apparent to the school that Rhys was suicidal.

"A teacher asks a question and she picks who has got the hand up first and they answer it incorrectly, that's when Rhys doesn't care about the social side or anything, he jumps straight in and lets them know 'no you're wrong and this is what it is' and he looks down at them. Then that's it, that cancels any socialisation with that person doesn't it".

"I got a phone call and he [the Deputy Principal] said 'listen I really need to see you, Rhys's been talking suicidal' and I thought oh no but before that I found something in a note and he wrote about hating his life and wishing he was dead and stuff like that and I started noticing that okay all my good knives are missing and I'd go in his room and check his room and they were in his draw and I wouldn't say anything, I'd just put them back and then it'd go again cause I always felt, I mean I can't really say this but I thought he'd never go that far".

A paediatrician prescribed an anti-depressant for Rhys, but he experienced side effects including mood swings and weight gain, which further decreased his self-confidence. He took the medication for three months before being taken off it at Sue's request. She reported that during this time his academic participation declined due to the depression.

"It started to affect his work a little bit as far as getting things done you know - he just wasn't interested, wasn't interested in going to school at all, did not want to go there".

Sue and the school staff worked together to support Rhys during this time.

"Just teachers involved, the school involved, just talking with Rhys, being aware of certain things and they'd update me, I'd update them, it was just constantly doing that you know".

Through this collaboration they were able to maintain his attendance at school. His transition to year eight initially went well. Sue reported that Rhys was well prepared by his primary school to start secondary school. The secondary school was also prepared for Rhys's arrival.

"They were all prepared, they were well aware of Rhys, he was allocated a case manager and he went through the Special Ed Department up there ...Leading up to high school he got to know his roll call teacher before he went. We had a couple of talk sessions up there with the head of department, the Special Ed Department up there ...and they set it up so Rhys would come every day and if there was a problem you know he could just get up out of the classroom and go straight up to the Special Ed Department. Teachers were to be aware

which they all were told of his condition and everything else so that set up was fantastic so I had no problems with him going there”.

Six months into year eight another negative turning point occurred. Rhys's social and academic participation went “straight downhill” according to Sue:

“[The school] were saying, “we can just notice his work’s not getting done, not properly finishing his work” and he was always one to make sure he finished it... The school started ringing me, I was getting phone calls at work – Rhys has come up to the office, Rhys has come up to the Special Ed Department, he won’t stay in the classroom”.

Sue attributed this decline to his difficulty navigating social relationships at school. Rhys did not wish to conform to the dominant culture of his peer group in order to be liked, instead he isolated himself at school and then refused school altogether.

“He just couldn’t communicate with them, you know they weren’t mature enough or they weren’t bright enough or he just didn’t fit. You know boys [would] get together and they’d do something silly or whatever and Rhys just couldn’t understand why, why do you do that? It’s just show off, it’s this; it’s that. So that you know, he secluded himself in one regard but then he was getting a little bit of a hard time I think from some of the kids anyway so he just retreated right into himself, that was it, didn’t want to go to school and that was why - he just couldn’t cope with the social side of it and it was a shame because he’s so bright and you know he was a good example in the classes because he’d sit there and just do his work and the minute he was finished, read a book”.

For several months Rhys refused to go to school. Sue and the school worked together to re-engage Rhys in school and he started attending again part time. This indicates the crucial role of home-school collaboration in enabling Rhys’s participation.

“I’d ring the school and say ‘are there any problems?’ [And they said] ‘Well yeah’ and I’d go up to the school, we’d work it out, so they stepped in as well and they said ‘well look let’s have so Rhys only goes so many days, we’ll start getting him back only coming so many days’”.

Sue enrolled Rhys in an AQ placement for the other three days of the week. Attending AQ was a positive turning point for Rhys as he successfully participated socially at AQ and his emotional wellbeing improved.

"He gets out there and plays at lunchtime and recess and all ... They're fantastic with him, he just comes home so much happier, you notice how happy [he is]. It's like a whole big weight's just been lifted off him. He's got six kids in his class including him so that's six overall. Well you know his teacher he's fantastic with him, Rhys really likes him so that's a bonus for a start, that is where I know he's going to make progress".

Sue acknowledged that Rhys was at a sensitive stage of life in terms of his mental health and she perceived that AQ acted as a buffer during this time.

"I'm protecting him by sending him to AQ now but he's going through puberty he's 14 turning 15, he's very vulnerable, he's at that sensitive stage. If he didn't have that I know what was going to happen, I know what avenues he was looking at ... he was getting, talking about couldn't stand life, wish I was dead, wish I wasn't born and when he gets like that and they're so emotional and they're in their room locking themselves in away from everybody and writing it down, you know that's not a joke, you know that's something they're really genuinely feeling and they can't help that feeling".

There were positive impacts on his academic participation at mainstream school due to the collaboration between AQ and his high school. In year nine, as indicated in the second extract, Rhys continued to do well academically in class, which his mother put down to his personal aptitude.

"The interaction between AQ and the high school is fantastic as far as his work and everything so. ... Keeping up to date with what he's got 'cause you know he can take his school work that he knows he has to have done, whether it be an assignment or something else to work on at AQ and they will allow him time on his own to complete that which is great".

"They haven't got a problem with his work, the education side of it because he's smart enough to cope with it all, you know he's actually in all the accelerated classes ... he's at least going now into the classrooms and every time the bell goes he's going to where he's got to go now because he knows it's only for the two days".

It could be interpreted that Rhys experienced cumulative advantage, for his positive early academic experiences at school was reinforced in later years. However, Rhys continued to have some difficulty participating socially at secondary school and experienced social exclusion.

"The socialisation is Rhys's barrier at the moment that's the only thing that's stopping him, that is the only thing. And he wants to break it he just doesn't know how. ...He just goes up to the special Ed thing. I think sometimes he stays out there and just sort of sits with kids that he know but doesn't really interact with them, you know he's told me that so you know he'll just hang there and just listen to them and yeah occasionally talk to one or two of them but that's about it you know and he knows that he's not included if you know what I mean like they're letting him know that okay you're there but you're not really included and that's the hardest thing and he's accepted that".

Sue reported that Rhys's case manager had been a significant source of support to both Rhys and herself during secondary school thus far. The case manager understood his condition and advocated for his participation in school activities. Moreover, she provided Rhys with a "safe haven" which he could access during lunch times if he was being bullied.

"Like he's got the case manager at the high school to ensure that they do get to participate in a lot of things that are going on ...he loves her [the case manager] because he knows that she understands what he is going through and he knows that she has as her job to help him be accepted".

"If lunch time is too much for him he's got somewhere to go [the Special Ed Department], someone to talk to, if he doesn't want to talk to anyone he's still got that somewhere to go to be on his own in a safe, friendly environment where he's not going to get name-called or something you know it's like a safe haven".

The case manager maintained communication with Sue and worked with her to support his academic participation at school. Sue perceived the case manager demonstrated an investment in Rhys as an individual.

"She involves the parents, she contacts me at home, if she sort of thinks oh Rhys not going to let Sue know that he's got this or that [due] and she'll do all that, you know via emails, via phone, outside of school time as well. I mean to me that is dedication and really caring about each individual kid that she deals with".

Although Rhys was attending school three days a week and doing well academically Sue expressed concerns about Rhys's future in mainstream school once his placement at AQ ends due to his continued difficulty with social interaction.

“That’s where it’s going to be hard like he goes; he wants to go to year 12. Well he thinks he wants to go to year 12. Once that stops [the AQ placement], I think it stops at 16 up there at AQ, yeah see he’s got to be able to blend in, not have somewhere to run, to stay in the situation and deal with the situation and that’s hopefully at AQ for the two years that will help as far as socialising”.

However, in terms of the future Sue was hopeful that Rhys would finish school and go on to university.

“He’s talked about going to university after year 12 which will be great. ...I think university would be good because you’re getting a lot of different people and they’re all there for that one thing if they’re serious”.

Rhys’s story illustrates his relatively stable school attendance, academic engagement and achievement. A number of factors seem to be implicated in his success including: access to early intervention; the willingness of schools to make adjustments; preparation for transitions and effective home-school collaboration. Key staff with an investment in Rhys’s inclusion also enabled his participation such as the deputy principal in primary school and his case manager in high school.

Rhys’s social participation has been less stable. At times in primary school he participated socially with his peers both in and outside of school, however at other times he has experienced bullying and social exclusion. While Rhys received social support from the school throughout his schooling he continued to experience social difficulties. The impact of these difficulties on his mental health has become more pronounced, as he has aged. In recent years he has experienced depression and suicidal ideation and this has impacted on his social and academic participation at school leading to a three-month period of non-attendance. Although Rhys is currently participating in mainstream school his mental health issues could impede his future academic engagement if they are not managed. This conclusion is supported by previous quantitative life course research in the United States by McLeod & Fettes (2007) into the educational trajectories of children with mental health problems using data from the Children of the National Longitudinal Surveys of Youth (NLSY) in which it was found that mental health problems influenced children’s educational attainment.

6.3 CHAPTER SUMMARY

This chapter identified two patterns of participation over time among the study participants: ‘disrupted participation trajectories’ and ‘relatively stable academic trajectories’. The majority who experienced a disrupted trajectory had frequent disruptions to their participation including restricted

hours of attendance at school, repeated suspensions and frequent changes of school. Previous studies on the schooling experiences of students with ASD by the National Autistic Society (NAS) in the United Kingdom (Barnard et al. 2000; Batten et al., 2006; Reid, 2011) have reported similar patterns of disrupted mainstream education for students with ASD characterised by frequent suspensions, exclusions and changes of school.

Only two students had ‘relatively stable academic participation trajectories’. One possible factor that may have contributed to students having either a disrupted or stable participation trajectory relates to behaviour. Those students in the disrupted group had reportedly displayed externalising behaviours and these behaviours were reportedly managed by their schools by restricting their hours of attendance or suspending them leading to restricted participation at school. In contrast, those students in the relatively stable group did not display such behaviours and therefore were present full time in the classroom (with the exception of one year of disruption in each student’s case). Previous research supports a link between the behaviour of students with ASD and their school participation. Yianni-Coudurier et al. (2008) examined the link between the characteristics of children with ASD and their weekly hours of regular classroom inclusion in a sample of 77 children with ASD aged three to five years using clinical data. They found that the children with more ‘aberrant behaviours’ had fewer hours of attendance in regular classrooms. Furthermore, the results of two American studies examining the Student Teacher Relationship (STR) between teachers and students with ASD indicate that student behaviours such as inattention, hyperactivity, impulsivity, opposition and defiance are all positively associated with relationships identified as ‘conflictual’ by the teachers (Blatcher et al., 2014; Robertson et al., 2003).

Across both participation trajectory types, a potential for change was demonstrated. Declan previously had a ‘disrupted participation trajectory’, but changed to a school at the end of year 11 that accommodated his learning needs and he went on to complete school and obtain his high school certificate. In contrast, Rhys’s trajectory was characterised by ‘relatively stable academic participation’ that was at times disrupted by his mental health problems. His experience highlights the multiple intersecting trajectories of the life course, in his case the interaction was between his education and mental health trajectories. In light of this, education and health sectors need to work together to support student wellbeing across their schooling. Collaboration between these sectors is a recognised core principle of good practice in education for students with ASD (Charman et al., 2011).

Two students' trajectories were used to exemplify the participation trajectory types and to explore influences on participation over time. Both illustrated the complexity of participation for students with ASD by highlighting the multiple factors that influence participation. Factors that enabled participation included: (a) a curriculum tailored to the student's language and cognitive abilities; (b) programs to plan and prepare for transitions into and between schools; (c) effective home-school collaboration, (d) programs to facilitate social inclusion and (e) effective case management. Furthermore, participation was enabled when school characteristics and supports matched with the students' characteristics and learning needs. Since both of these change over time, enabling participation is an ongoing and dynamic process. This echoes the conclusions of Ainscow et al. (2006, p. 25) who state that inclusion is "a never-ending process. Thus an inclusive school is one that is on the move, rather than one that has reached a perfect state".

This chapter has built on the results of the previous chapter by developing an understanding of the participation trajectories of the students in this study. It has provided two in-depth trajectories to demonstrate the participation trajectory types and has explored how transitions, turning points and cumulative influences were perceived to have shaped the students' participation trajectories. The next chapter will discuss parents' experiences of supporting their children's participation in mainstream school over time.

CHAPTER SEVEN: THE PARENT EXPERIENCE OF SUPPORTING THEIR CHILDREN'S PARTICIPATION IN MAINSTREAM SCHOOL

In this chapter analysis of the parents' experiences of supporting their children's participation in mainstream school over time is presented. Conceptually the analysis, which integrates the first and second parent interviews, was informed by the life course concepts of linked lives and human agency (Elder & Giele, 2009). In this case, the analysis reveals how parents' experiences interface with their children's experiences. It also indicates parent's sense of agency in terms of influencing their children's participation in mainstream school and how parents' agency was enabled or constrained by structural arrangements. Parent experiences were characterised by one central theme - 'the perpetual battle'.

7.1 PRINCIPAL THEME: THE PERPETUAL BATTLE

It was evident that mainstream participation of their children was linked to a 'perpetual battle' by parents across the schooling years. Although parents expected mainstream schools to provide inclusive educational provision that met the changing needs of their children, there was often a discrepancy between these expectations and what they perceived was actually provided. Consequently, parents engaged in 'constant advocacy' (sub-theme one), performing a number of roles: monitoring schools; educating staff about ASD; and advocating for educational adaptations to be made for their children. However, there were barriers within school contexts that substantially constrained parents' ability to advocate and influence their children's participation experiences. These included: lack of communication from the school and parents perception of school expectations regarding their role. In most cases, despite engaging in this 'perpetual battle' the general perception was that their children did not receive an appropriate education in mainstream schools that met their individual needs. The 'perpetual battle' was time consuming and impacted on many facets of parents' lives indicating that their lives were linked to those of their children. It led to 'altered lives' (sub-theme two), effecting parents' career trajectories, mental health and relationships with their children and families of origin.

7.1.1 Sub-theme one: Constant advocacy

Parents perceived they had to take an active role in their children's education if their children were to be provided with an inclusive education in mainstream schools that enabled them to participate. This involved becoming a constant advocate for their child as Hayley described:

"It was just constant you know and if you didn't become an advocate you'd lose your son or your daughter because you can't always have the school being right you know and the school's never going to develop if they aren't told some of the truths that they need to hear" (Hayley).

The point at which parents took an active advocacy role in their children's education varied. Most took one from the outset as their children experienced barriers to participation upon entering the schooling system, whereas two were initially passive and only became active advocates when their children's participation decreased at a later stage in their schooling. For example, Jemma reported that she did not become an advocate until her son Brad was in year five. She reported during this year Brad was unable to participate in classroom activities due to a conflictual relationship with his teacher and this meant she needed to intervene.

"Year five I started to, I really realised that there was, I needed to start to address things I guess" (Jemma).

Advocacy involved a range of activities such as monitoring, educating and negotiating for adaptations. It is important to note that not all parents engaged in all activities, though all engaged in one or more. Some parents perceived they had to constantly monitor schools practices. The experience of one parent is provided below to illustrate the use of monitoring. Julia perceived that if she did not engage in constant monitoring the school would not provide an inclusive education for her son Jake.

"You've just got to really basically be at the school every day seeing if something has changed, if things are being moved on – information, even ringing if you can't get there, ring and see, find out what is going on – has there been any problems? Do you need to have a meeting about something? You've just got to, for me I found you just have to keep on them, you just had to be in their face all the time... making sure that they are doing what they're supposed to be doing and just riding them" (Julia).

In her interviews, Julia expressed a lack of trust in the school's ability to provide an inclusive education for her son and this appeared to stem from her prior experience of the school not following through on promised adaptions for her son. For example, she described how the school had said they would provide a laptop for her son to use instead of handwriting but had failed to provide one, and after several years she finally purchased it herself.

This experience is similar to that reported by parents of children with ASD in a study by Stoner et al. (2005) who interviewed four couples who were parents of children with ASD about their perceptions of interacting with educational professionals in the United States. Stoner et al. (2005) found that parents previous experiences with education professionals had the potential to result in a reduction of parental trust in the teacher and once this reduction of trust occurred parents became “increasingly watchful and diligent in their efforts to ensure that their child received all services they deemed necessary to meet the needs of their child” (Stoner et al., 2005, p. 45). When parents reported low trust, their engagement in monitoring increased (Stoner & Angell, 2006).

Some parents in this study reported that they had to constantly educate school staff about their child and the condition of ASD as each year the classroom teacher would change. An example of one parents experience is described below. In the excerpt Hayley describes her constant effort to educate her son’s school and her strategy for providing information about her son’s educational needs to his teachers. Her excerpt indicates that this strategy was perceived to be successful in primary school, but was unsustainable once her son entered secondary school. A possible explanation for this relates to the secondary school context. Students have contact with up to six different subject teachers and it may have been difficult for Hayley to ensure information was shared amongst all of these teachers.

“Every year you’ve got like different teachers, you’ve got re-educate a whole new set of people and you get the same problems cropping up but you just have to continually re-educate the same people over and over again...I actually did develop a sheet - it was called the ‘Declan mail’ and it basically outlined his strengths and weaknesses and I updated that every year and I would give that to the teacher to pass on to his new teacher. And that worked okay while he was in primary school, but once I got into high school it was hopeless to try and do something like that” (Hayley).

Hayley’s experience highlights how school environments change over time and therefore facilitating student participation is an ongoing process. Not only did Hayley educate her son’s school about the impact of his ASD on his education, when her son was in secondary school she also educated the staff via a presentation about the impact on her family. Hayley perceived that her presentation to school staff was successful as it “opened some people’s eyes” to the experiences of her family members. Her excerpt indicates the school were willing to create the opportunity for Hayley to educate their staff as they extended the invitation.

“They actually did ask me to go over and give a talk to the staff about our journey with Declan... basically I let them know how stressful it is as a parent to have a child with autism... this is the effect it has had on us as parents, this is the effect it has on our daughter and you know at school you see this part of it, but this is what we have to cope with at home” (Hayley).

Parents perceived they were often caught in the middle between the school's expectations and their child's. One example of this was in relation to schoolwork. Half of the parents reported that schools expected them to support their children to complete unfinished schoolwork at home, but that their children did not wish to do so. This was a source of stress for parents as the following excerpt from Glen indicates:

“If he wasn't doing the work at school it was being sent home with him ‘he needs to complete of this’ so then we would be sitting here pushing him to do all this work – ‘we need to do this’ ‘nooo’. So not only were we battling them, but we were battling him” (Glen).

In cases where the school's expectations and their child's differed parents acted as negotiators in an attempt to reach a middle ground as Hayley describes:

“I've done a lot of work in trying to educate teachers, trying to communicate with the school to communicate with Declan, like being a third party sort of thing. So you know the school wants this, Declan wants this and we come to come sort of arrangement you know” (Hayley).

Parents also felt they had to constantly advocate for a range of adaptations to be made so that their children could participate in mainstream schools as Anna describes:

“Constantly letting them know what he can and can't cope with. Constantly asking for programs to be adapted so that he can access them. Constantly wanting an environment that he could cope with. Constantly trying to keep bullies away from him. Constantly trying to educate people to look beyond the behaviour because there is a really nice kid in there and unfortunately people just see that big, gruff, loud Paul and they don't look at that person that will make an omelette with a love heart on it for mother's day. They're not getting to see that in him because they haven't got the environment, the workload, even the peers right for him to cope. So how have I had to advocate? In every way!”(Anna).

Anna's excerpt highlights the multiple barriers to participation her son Paul experienced in mainstream schools in relation to attitudes, environment, curriculum and peers. In the trajectory chapter Paul's story illustrated these multiple barriers and demonstrated that despite Anna's constant advocacy Paul experienced a restricted and disrupted pattern participation in mainstream school over time.

Successful advocacy required schools to be open to working with parents and to be willing to make adaptations for the child. Parents' varied in their experiences of collaboration. For example, Sarah reported encountering a "brick wall" when attempting to negotiate for adaptations at all the mainstream schools her daughter had attended. Her excerpt indicates a perceived inflexibility on the part of school staff to change their attitudes and practices:

"Advocacy is only good if the other people are going to change the way they see things and the way they do things and that's the reality and that's what I mean when you come up against a brick wall. I feel like I've been up against a brick wall from the beginning with every school" (Sarah).

Anna also experienced inflexibility in all of her son's schools when attempting to advocate for him but attributed this to the limitations of broader school policy rather than attitudes:

"Policies of the school, it's very hard, they've got to work between their guidelines so until those guidelines get moved I think everyone is going to continue to bang their head. They can only do so much...Because they've got to conform between this line and this line and there's no area for grey, it's black and white and this is what you do and if the kid doesn't fit you move him on" (Anna).

In both cases parents perceived that inflexibility on the part of schools was the dominant force shaping their advocacy efforts, not individual factors such as their communication skills. This suggests that these parents' agentic efforts were heavily constrained by structural factors.

In contrast, several parents reported that they initially had a collaborative relationship with their child's school but this was disrupted in later years by a change of staff. The disruption to their relationship with the school consequently reduced their child's participation. For example, Brendan's father Glen described being excluded from decision making about managing Brendan's behaviour at school when a new principal acquired the position, which resulted in Brendan being disciplined for behaviour that was ASD-related:

"In primary school we had a good relationship for a long time with the school where we were working with them and they were working with us, it seemed to be a working partnership. Obviously we had a change at the helm with the change of principal and it went from an area where we were both trying to achieve an outcome with Brendan to where it's like 'well no we're going to manage him within the school disciplinary framework and you can ring me up all you like but I'm not going to change my mind' ...So we went from 'let's talk about it' to 'no, I've made the decision and I'm not discussing it, I'm not changing it, I'm not altering it, this is what is going to happen'" (Glen).

Regardless of whether collaboration had been experienced, all parents acknowledged the paramount importance of teamwork with the school to enabling the participation of their children as illustrated by Hayley:

"I think that you really need to be a team with the school, that's from day one if you know your kid is a little bit different you need to be with the school and working out how to most, to make them as successful as they can be given whatever limits you might have. So I would say that's the one thing – teamwork and if the school's not going to work with you, find a school that will work with you because that's the best way to do it" (Hayley).

Hayley's excerpt also highlights the importance she placed on the school's willingness to work with parents as she indicates that if a school is unwilling, parents should find another school that is.

Parent perceptions varied about whether or not they had experienced barriers to their advocacy efforts. Two parents (Jemma and Sue) perceived they had not experienced any barriers.

Interestingly, these were the parents of the children with relatively stable academic participation trajectories so their children's slightly more positive experience in mainstream schools may have shaped their perception. However the rest reported that their advocacy efforts were constrained by either: lack of communication from the school and/or by their perceptions of school expectations regarding their role.

Three parents reported that a lack of communication from the school led to them feeling like they were uninformed about their children's experience of participation at school, which made it hard to advocate effectively on behalf of their children. For example, Julia said: "there was a lack of communication, a lack of everything". Parents reported that they had to rely on the schools to provide information about how their children were participating at school, as their children did not

communicate much to them about their experiences at school. This was not always forthcoming from the school. During their interviews Philip and Hannah commented that it was difficult to describe their daughter Claire's participation in secondary school, as they had no communication with her school as Hannah indicated:

"[The teacher] told us when we went [to the high school] that they were going to send emails to say how your kid was going and I haven't received any" (Hannah).

Three parents perceived there was a lack of communication from schools about special education funding and that schools were not transparent about how it was used. This made it difficult for parents to advocate for changes to their children's special education supports. Parents demonstrated misunderstanding about the way in which special education funding is allocated in Queensland schools as they believed funding was directly allocated to each child when in fact it is allocated in a block based on the number of students with a verified disability at each school (Education Queensland, 2014). Therefore in the absence of communication from the school about this, parents believed that schools may be misusing their children's funds and this fostered a sense of distrust in the school as indicated by Julia:

"Funding is a big thing for me. I'd love to know where it all went, I'd love to know, and I'm sure they'd make up some bullshit as to where it went. Oh we had to buy pens or we had to buy this, I think the amount of money they get for an autistic child is \$15 000 per child so I can understand some going towards wages, bit towards buying stuff, but Jake wasn't the only child, so where did the rest go? I don't think it went to the special, it did not go to the special needs unit, it didn't, it just didn't, you could see it didn't" (Julia).

These findings parallel those of Stoner et al. (2005). In particular, the finding that in their engagement with education professionals, parents had "an intense need for frequent, open, and honest communication from teachers for two reasons: (a) because a lack of communication fostered distrust and (b) due to their son's pervasive communication disorder" (Stoner et al., 2005, p. 45). Three of the four children of the parents in the study were non-verbal so parents had to rely entirely on schools for information about their children's progress at school. Interestingly, in the current study all the of the students with ASD were verbal, however their parents still perceived that their children did not communicate with them about school. This may be because social and communication difficulties are a core feature across the spectrum of children with ASD (APA, 2013). This reinforces the need for schools to communicate regularly with the parents of children with ASD.

Some perceived that their advocacy efforts were also constrained by school staff members' expectations regarding their role. Four parents perceived that school staff members expected them to be passive, agreeable, non-experts. This placed parents in a difficult position as they also perceived that they needed to be "in their face" at school in order to advocate for their children. Therefore they attempted to achieve a balance between the two. When parents were too assertive in their approach there appeared to be negative consequences for them. For example, two parents described how they perceived they had been labelled "troublemakers" at their children's schools. Julia expressed a feeling that school staff "dreaded" her, as she had become a vocal advocate for her son:

"I think they dreaded me saying 'I'm coming up'. Oh god it was just terrible, yeah I think they dreaded me coming up, they preferred my husband cause he was more placid" (Julia).

Philip, one of the fathers had Asperger's syndrome himself and reported that he had a frank communication style that made school staff "turn off". Consequently he was unsure how to communicate with his daughter's school for fear it would be misinterpreted as the following excerpt indicates:

"I don't know what to say 'cause when I do it causes chaos and mayhem. They think I'm being a nasty bastard and I'm not, that's how I think" (Philip).

Philip took action to improve his relationship with the school. He attended a Positive Partnerships training program for parents focused on assisting parents to form mutually beneficial partnerships with their child's school (Department of Social Services, 2014). However he perceived his participation in this program had not improved his relationship with the school or his daughter's experience there. He reported the school staff saw themselves as the experts. He stated their attitude was: "we're the experts and you're wrong". He felt this attitude meant his lived experience of ASD and parental knowledge was not valued by school staff which then deterred him from further communication with the staff of his daughter's school.

A further two parents perceived they were at risk of being adversely labelled by schools. Parents perceived that if labelled they, and their child, could be excluded; and this deterred some of them from assertively voicing their concerns about their children's restricted participation at school. For example, Sarah worked at her daughter's school and observed in meetings how other vocal school parents were labelled and subsequently treated by the staff. In this extract she described her

perception of the tactics used by the school to remove a parent and their child from the school community:

"I learnt when I was on that committee that parents who were constantly in their face that it would get to the stage that they would want to get rid of that parent...The person wasn't a person anymore they were a problem okay and once they became a problem, how do we get rid of this problem? ...So if the parent was angry, angry, angry cause their child was always getting suspended but they felt their child shouldn't be suspended because they have a disability or problem - we'll just keep suspending them and they're going to leave at some stage...I learnt really quick that the parents that were in your face the most not only got the labels but didn't get a lot of time, didn't get a lot of empathy, the principals and that, it didn't help their children, they just wanted them out in the end" (Sarah).

Since school staff members were not interviewed as part of this study their perceptions of parents are unknown. Despite this, it is evident that parents' perception that they were being labelled, or were at risk of it, shaped their involvement in their children's education and in some cases deterred them from assertively advocating for their children's educational needs to be met.

Parents' perceptions varied on the extent to which their advocacy efforts had increased their children's participation in mainstream schools. Five parents perceived that even after advocating for adaptations to be made to facilitate their children's participation for many years the system remained unchanged and therefore their children's participation remained restricted. Over the course of their children's schooling they had repeatedly resorted to changing schools in search of a more inclusive school placement for their children, however most did not succeed in finding one.

Consequently their children's experience overall was characterised by disruption and restricted participation. Some parents interpreted this as being a result of mainstream schools being uninterested in providing an inclusive education for their children with ASD as illustrated by Sarah:

"I feel as if no-one really wants to help. I feel like they just want to palm us on to the next school. It's too much trouble and I feel like they know the politics, if we do nothing for your child but the bare minimum we're within what we're supposed to do but you're going to move on to find somewhere else because you're the parent and you're advocating for your child" (Sarah).

In this case, Sarah's perception was that schools actively attempted to rid themselves of her daughter by providing the "bare minimum" and taking advantage of her concern for her daughter's

best interests. Since school staff members were not interviewed it remains unclear what their intentions were. However, in two previous international studies incorporating the perspectives of school staff about their attitudes and practices towards the inclusion of students with disabilities school principals have reported that they do not always perceive they are responsible for providing an education for students with disabilities in their schools (Kearny, 2009; Watson, 2009). In the study by Kearny (2009) in New Zealand some principals reported a belief that inclusion is not possible when children are ‘too disabled’. In the study by Watson (2009) in Ireland some principals reported a belief that inclusion is predicated upon access to resources and reported that they used their position to dissuade enrolment of students with pervasive developmental disabilities citing their schools lack of capacity to provide adequate resources as the rationale. These findings suggest that some principals place qualifiers on the inclusion students with disabilities and may not perceive they are responsible for providing access to an education for all students.

Parents’ experiences of moving from school to school and constantly advocating for accommodations to be made with little success appeared to have had a cumulative effect on their involvement in their children’s mainstream schools. Four parents (Anna, Sarah, Julia and Philip) described being “worn out” or “too tired” to continue the battle with mainstream schools as described by Anna: “I’m beaten down. I don’t have any more fight in me”. This led Sarah and Julia to remove their children from the mainstream schooling system altogether. Philip had not removed his daughter but was considering home schooling. These parents interpreted their children’s negative experience as being due to the education system failing their children as illustrated by Julia:

“I feel as if the education system is the one that failed, because we tried. We tried everything we possibly could to get everything right; to get him to be happy, it’s all we wanted him to be was to feel happy and safe... I pray it gets better and it sounds terrible to be saying but I don’t think it ever will...it hasn’t, we’ve been fighting it for nine years now, longer and it hasn’t, it hasn’t improved, if anything it’s got worse...he’s now being home schooled. So that’s not, I don’t see that as being a positive thing for the education system, the education people, I mean it’s just not. They’ve failed him” (Julia).

In these cases parents perceived that removing their children was the only way to reclaim control over their children’s education and ensure they received an education appropriate to their individual needs as Julia expressed.

"I'm in control, I know he's going to get an education, it's one on one, I can watch what's happening, I can help him, I can support him. No-one's going to support him better than I can. He's safe, he knows he's safe and I think he'll pick up quicker, he'll be able to catch up on the stuff he's missed out cause he's getting that one on one stuff and he'll be able to get routine" (Julia).

The fourth parent, Anna, had not removed her son; however he was excluded from special school during the time the study was conducted. She blamed both the system and herself stating:

"I feel like a failure, like you've failed your child. You've tried and you've tried and you've tried but in the end I think I've failed him. The system has failed him, the policies have failed him. Not so much the individual teachers. But yeah you've failed. So I daresay that gets you quite emotional, it gets you sad, gets you down thinking of the long term what to do now" (Anna).

In contrast, two parents (Hayley and Sue) perceived their advocacy efforts had a positive impact on their children's participation in mainstream school. Hayley felt she had some success in the sense that she had maintained her son in school: "I don't think he'd still be in school if it wasn't for me advocating for him". Sue perceived that her advocacy efforts were entirely successful as her son Rhys was attending school fulltime and succeeding academically. She reported that her success was due her willingness to listen to "experts" and work with them.

"I think my bonus is that I've got out of things and been able to help Rhys a lot more is because I have listened to people that are classed as the experts and I have shared and I have made sure I haven't closed doors you know" (Sue).

Sue reported that in both primary and secondary school the staff had been willing to work with her and to make accommodations for Rhys. Hayley made similar reports about the staff in Declan's secondary school. Therefore a school's facilitation of parent participation appears to impact on their involvement in their children's education. This finding is supported by previous research on maternal involvement in the education of students with ASD by Benson et al. (2008) who surveyed 95 mothers of children with ASD about their educational involvement in the United States and found that school willingness to collaborate with parents and facilitate their involvement through meetings and phone calls was the single most important predictor of maternal involvement in their children's education.

7.1.2 Sub-theme two: Altered lives

Over the course of their children's schooling the 'perpetual battle' had a significant, negative impact on most parents' lives and those of their other children. Sue highlighted the linked nature of parents' and children's lives when she said: "it hits every aspect of your life, your family's life, the siblings life". One parent, Jemma, was the exception. Jemma did not report any negative impacts on her life. Interestingly, Jemma was the least involved in her son's education over the course of his schooling and had only engaged in a 'perpetual battle' in the last three years. It appears that for most parents the 'perpetual battle' had consumed much of their lives as Julia's excerpt indicates:

"You're spending 70-80% of your time trying to get somebody to listen to you to get your kid settled that you've only got 10% left here, and 10% left there [referring to her two other children] and nothing left over for you" (Julia).

Parents of students in the 'disrupted participation trajectory' group perceived that they had had to be on-call at all times to supervise their children when schools restricted their participation. The majority of parents reported numerous instances over the course of their children's schooling where they were asked to collect their children before finishing time because the school had restricted the students' hours of attendance following a behavioural incident.

"I was really sorry at one stage that I got a mobile phone cause that meant I was always contactable...in later years like I think from year four on I was probably picking up and taking him home quite a bit" (Hayley).

Another example of being on-call was in relation to school camps. Two parents reported being asked to find accommodation near their children's school campsites and were expected to remain on stand-by. In both cases the parents were called to collect their child before the camp finished as Glen described: "He only went for half the time. Yeah they really didn't want him there".

"It must have been year five I think and he wasn't allowed to go on camp unless I went and stayed close by so I had to go and stay in a caravan park down the road from the place at Kenilworth and they would call me if I needed to go and pick him up" (Hayley).

Parents' experiences suggest that they were being co-opted by schools to fill gaps in the system. In instances where schools would not take responsibility for managing the children with ASD parents were expected to provide supervision either during school camp time and/or during regular school hours. Although this may also be expected of parents of typically developing children in limited

situations, for example when a child is sick a parent may be asked to collect them early, what is alarming in this study is the regularity with which the parents had been called upon to supervise their children with ASD during school hours.

This had significant repercussions for parents' lives, for example, in some cases parents had to alter their career trajectories to be available to respond to frequent phone calls from schools, to collect their children before finishing time and to supervise their children when their hours at school were restricted. Some parents reported that they had reduced their hours of work and others had given up work entirely. Two parents discussed the need to change from professional careers to retail jobs in order to obtain more flexible working arrangements. One of these parents had already changed careers. Anna had trained as a nurse but was now working in online retail so that she had more flexible hours. The other parent, Sarah, reported that although she trained as a youth worker, when she returns to work in the future she intends seek employment in retail as she perceived she could earn a higher income while working less hours:

"I'm probably going to have to do some sort of hard labor type work you know like packing shelves, something which pays high to bring in some money... but I can't afford to be a youth worker anymore. They don't pay enough for me to be able to bring in enough money for the hours at all and the volunteer hours that you put in in a job like that are big as well" (Sarah).

Although parents did not describe the emotional impacts that their changes of career had on their lives, a recent study by Stoner and Stoner (2014) provides insight into the emotional impacts of career disruption on the lives of parents with ASD in the United States. The parents in the study grieved the loss of their careers and experienced a sense of isolation and loneliness and underutilisation. This illustrates the profound emotional impact that career disruption has on the lives of the primary care-giving parent (Stoner & Stoner, 2014).

For those parents in the study who were able to maintain employment throughout their children's schooling the importance of having an understanding, flexible employer was emphasised, for example Hayley said:

"I spend an inordinate amount of time going to the school and doing stuff at the school you know, to the point where sometimes it puts my role here in jeopardy. I think I said last time

that you have to have really understanding employers you know because you couldn't function, I couldn't function in a normal sort of job" (Hayley).

For those parents with reduced ability to work there was a flow-on effect on family finances and most parents reported experiencing financial strain. This was particularly noticeable for one family in which both parents (Glen and Mary) were self-employed as any time they took off work to be at their son's school meant that they were not earning an income for their family as the following excerpts indicate:

"Basically every time I tell someone [the client] I'm going away well that's \$130 per hour. Cause I can't charge them if I'm not there" (Glen).

"Cause he's not on a salary so he only gets paid when he works" (Mary).

The financial strain of missing work was coupled with the substantial ongoing costs of specialists for their children with ASD, which meant families were doubly disadvantaged. This had serious implications for two parents, Sarah and Julia. Both parents reported that they were at risk of financial ruin and both expressed concern in relation to their family homes. Sarah was currently concerned about her ability to keep up with the repayments on her family home and was concerned her family may lose their house:

"We bought this house cause of the \$21, 000 grant and now it's too expensive for us because we've only got one person working and the prices of houses have dropped so we're just between a rock and a hard place. We have to try and keep this house until the prices increase again so that we can then sell and go somewhere we can afford but at the moment we can't afford to lose on it because we won't be able to live at all" (Sarah).

Julia described having to sell her family home in the past:

"It's had a huge financial [impact]. I think at one stage we thought we were going to lose everything, just lose everything. We'd just bought a new house and we had to sell it, cause we couldn't do it anymore which causes more stress" (Julia).

The 'perpetual battle' affected the mental health of some of the parents in the current study. Four parents reported suffering mental health issues such as depression at some point during their children's schooling. Three of these reported being on antidepressant medication in order to manage

at the time of their interviews. The remaining parent reported she had previously taken medication, but was not at present. Sue describes her experience below.

"It's like you took it all on board which can be dangerous to yourself to the point I did get really depressed and I just thought 'what the hell' you know so I got myself on tablets and I was on them for years... I only just got off depression tablets not even a year ago" (Sue).

The parents who had experienced mental health problems perceived that their children's negative experiences at school directly impacted on their mental health. A recent quantitative study by Barker et al. (2011) indicates a more general link between the characteristics of children with ASD and maternal mental health trajectories. In their study on emotional wellbeing of 379 mothers of adolescents and adults with autism, they established that maternal wellbeing trajectories were sensitive to fluctuations in both child and maternal context variables. Their finding demonstrates the linked lives of children with ASD and their parents and the reciprocal influence on each other's lives.

Multiple relationships within parents' lives were affected by their 'perpetual battle'. Nine parents indicated that their marriages were affected to different degrees. Some reported that they had experienced marital stress at some point. This stress appeared to stem from the different roles undertaken by fathers and mothers in supporting their children's participation at school. In most cases it was mothers who took primary responsibility for battling with their children's schools. Several mothers reported that their husband's lack of understanding of their battle caused tension in the marriage as indicated by Hayley:

"I guess my husband and I's marriage is still together but it could quite possibly not be because particularly in the early years when my husband didn't understand, he wasn't going to all the school stuff, I was doing all that and he's just thinking that this kid is naughty or whatever" (Hayley).

Hayley's quote indicates that in the earlier years of her son's schooling she and her husband experienced tension. However, she reported in her interview that their relationship had improved in recent years after her husband attended parent workshops on ASD and through doing so developed a better understanding of the condition and appreciation of the crucial role Hayley played in supporting their son's participation at school.

In contrast, three of the parents (all mothers) reported that there had been a complete relationship breakdown with their husbands at some point in their lives leading to a divorce. In all of these cases mothers perceived that the reason for the breakdown was that their husband remained unable to manage the child with ASD. For example, Anna indicated: “He can’t cope with Paul, so therefore it cost the marriage”. In these cases the breakdown of the marriage was not perceived to have been directly caused by their perpetual battle with the schools, but rather was attributed to their broader experiences of parenting children with ASD. Two of these parents had since remarried and reported that their new husbands were more understanding of their children with ASD. For example Laura said: “He’s got a new dad now. A good one this time. Luke worships the ground he walks on”.

There were also varying impacts on parents’ relationships with their families of origin. Most of the parents perceived there was a lack of understanding from their families and also commented that they were isolated from family activities. Most also reported that they did not receive support from their family of origin. For instance Julia commented: “There was no support from family, none ...they’re just not interested, and it’s our problem sort of thing”.

In contrast, one parent reported that her mother provided her family with financial support in order to enable her to home school her daughter. Although this financial support was acknowledged to be crucial, it had a negative impact on both parent’s self-esteem in relation to their perceived capacity to provide for their family as Sarah reported:

“Well my mother is basically supporting us with my additional wage which just totally tears your self esteem, you know I’m an adult, my husband is a lawyer for crying out loud and he earns a good wage... He has always been really up there with providing for his family and that sort of thing, you know he’s not able to make that now and for his self esteem and his self worth it’s devastating, and it’s hard on our relationship... you just feel like a kid again, you feel like you can’t even take care of your own family, you can’t even look after yourself”
(Sarah).

Parents varied in their perceptions of the impact of their perpetual battle on their relationships with their other children. Some did not report any impacts, whereas four parents reported that their relationships were negatively affected. They reported that their other children were resentful towards them for all the time they had spent addressing the needs of the child with ASD. For instance Hayley said:

“You know very much she thinks she’s not getting the attention that she should get and sometimes she wasn’t because you just physically couldn’t give it you know you had to respond to a crisis and so she was justified in feeling that” (Hayley).

Hayley also commented on the stigma her daughter experienced while at the same school as her son with ASD:

“When they both went to the same school she’d get tagged with his brush or you know everybody would tell her all the bad things Declan did and not give her a chance to be her own person” (Hayley).

This excerpt indicates the linked lives between siblings and the potential issues faced by siblings attending the same school as their brother or sister with ASD.

7.2 CHAPTER SUMMARY

Across the schooling years as a whole, parents’ experiences of supporting their children’s participation exemplified a ‘perpetual battle’. Notably, this battle involved great persistence on the part of parents to have mainstream schools recognise and accommodate their children’s needs and at times, it was all-consuming. Some parents’ relationships with schools became adversarial. This finding supports the existing literature, which has described parent’s involvement with the education system in a number of countries as one that involves a ‘fight’ for provision (Batten et al., 2006; McDonald, 2010; Penney, 2013; Reid, 2011; Stoner et al., 2005; Stoner & Angell, 2006; Tissot & Evans, 2006).

In most cases parents perceived that their ‘constant advocacy’ had not improved the participation of their children. Parent’s ability to exercise their agency was constrained in some cases by lack of communication from schools. Without communication from the school parents felt uninformed about their child’s experience of participation at school and this made it difficult to discern whether or not advocacy was required. It may have also fostered a sense of distrust in educational professionals, as was reported by parents in a previous study by Stoner et al. (2005).

Parents’ agency was also constrained in four cases by their perceptions of the attitudes of school staff towards them (e.g. that they were, or could be labeled as ‘difficult’). These perceptions shaped their involvement in their children’s education by deterring them from assertively advocating for their children’s educational needs to be met. Similar results were reported in Stewart’s (2012, p. 23)

study of 151 parents of children with ASD in Northern Ireland in which many parents reportedly perceived that appealing to the Tribunal led to them being labeled as a “difficult parent” by the school and other parents in the study reported that they were unwilling to challenge the school out of fear that “things will get worse for their child”. If parents feel discouraged from advocating to increase their children’s participation in mainstream schools for fear of being labeled by these schools this may have negative consequences for their children as they may continue to experience barriers to their participation. This suggests the need for school staff members to actively encourage and facilitate equal partnerships with parents.

Half of the parents in this study experienced obstacles to forming partnerships with schools. So not only were the students excluded but so were their parents. This contravenes best practice literature on inclusion of students with ASD, which states that home-school collaboration is essential and that partnerships with parents should be fostered (Guldberg, 2010; Parsons et al., 2011; Roberts & Prior, 2006). There were examples of effective home-school collaboration (e.g., Hayley and Sue), which raises questions as to why this was not possible in the majority of cases. It could be that teachers did not see it as their role to engage with parents or value parent expertise. It could also be that teachers are in fact willing, but time and resource constraints made it difficult for them to follow through, as was reported by Australian teachers in a previous study of teacher perceptions (See Forlin et al., 2008).

The results highlight the linked lives of parents and their children with ASD. The level of input into education required by the parents was very extensive and well beyond what might be experienced by parents of typically developing children. This mirrors the findings of the broader literature on the lived experiences of parents with ASD in which the intensive role of parents in the lives of their children with ASD has been described (Ryan & Runswick Cole, 2009; Woodgate, Ateah & Secco, 2008). For example, Woodgate et al. (2008, p. 1079) conducted a phenomenological study of the lives of 21 parents of children with ASD in Canada and coined the term “vigilant parenting” to describe parents experience of becoming “super-parents” who were entirely focused on their child’s lives and displayed “a heightened sense of watchfulness and preparation for action”.

Caring for a child with ASD is already stressful for parents and the conflict with schools has placed additional stress on the parents in this study. The bulk of the advocacy work fell on mothers’ shoulders. This has had an impact on their careers and an emotional, social and financial impact on them and the rest of the family. These findings emulate those of many previous studies on the

experiences of parents of children with ASD where parents (particularly mothers) have reported wide ranging impacts including: reducing or giving up employment (Batten et al., 2006; Bourke-Taylor, 2012; McDonald, 2010; Reid, 2011; Ryan & Runswick Cole, 2009; Seltzer et al., 2001) decreased household income (Cidav et al., 2012; Montes & Halterman, 2008); mental health issues (Barker et al., 2011; Montes & Halterman, 2007; McDonald, 2012; Sawyer et al., 2009) family breakdown (McDonald, 2012) and family isolation (Gray, 1993; Woodgate et al., 2008). This indicates that the effects of the exclusion of children with ASD are far reaching and that schools must consider family needs and mechanisms for support need to be put in place. Family support has previously been acknowledged as a key principle in good practice in ASD education (Charman et al., 2011). There may also be a role for allied health professionals in the broader community to assist parents in developing their informal social support networks.

Three parents in this study ended up removing their children from the mainstream education system. Several had attempted or were currently home schooling their children. This is consistent with the extant literature, which indicates an international trend of parents of children with disabilities increasingly choosing to home school because their children experienced inadequate provision in mainstream schools (Hurlbutt, 2011; Kidd & Kaczmarek, 2010; McConnell, 2006; McDonald, 2010; McDonald & Lopes, 2012; Parsons & Lewis, 2010; Reilly et al., 2002). This seems to be one way that parents seek to regain control over their children's education. Research by Kidd & Kaczmarek (2010) exploring the lived experiences of 10 mothers of children with ASD home educating their children in Australia indicates that some parents perceive that this option enables them the flexibility to cater to their child's unique learning needs and parents report improvements in their children's academic progress and emotional wellbeing as a result (Kidd & Kaczmarek, 2010). They also report gaining a "sense of power and control over their situation compared to when their child attended school" (Kidd & Kaczmarek, 2010, p. 269). However, several other parents felt forced to home educate their children and experienced a loss of control (Kidd & Kaczmarek, 2010). Since a growing number of parents are choosing this option greater financial and social support and resources should be provided to support these parents to enable them to succeed (McDonald & Lopes, 2012). Simultaneously, reforms are necessary to reduce the barriers to participation for students with ASD in mainstream schools so that parents feel they have a real choice to place their children in these schools and can feel confident that appropriate provision will be provided for them.

This chapter has developed an understanding of parents' lived experience of supporting their children's participation in mainstream schools over time. It enriches the findings of the previous chapters by providing insight into the intensive nature of parents' involvement in their children's education, including the different roles they engaged in, and the range of impacts on their lives. The final results chapter will examine how students experienced participation in mainstream school.

CHAPTER EIGHT: THE STUDENT EXPERIENCE OF PARTICIPATION IN MAINSTREAM SCHOOL

In this chapter analysis of the student interview data is presented. The analysis was guided by the research question: how do students experience participation in mainstream schools? In this chapter, the students' experiences of both social and academic participation are described and interpreted. Where required, parent data has been used to provide additional contextual information to assist in understanding the student experience. From Life Course Theory (Elder & Giele, 2009), the ideas relating to timing, human agency and linked lives provided the theoretical concepts to deepen the analysis and interpretation of the data. Students' experiences were characterised by two dominant themes: 'academic mismatch' and 'standing out'. Quotes are used to illustrate the themes. The selected quotes are representative of the students' experiences.

8.1 THEME ONE: ACADEMIC MISMATCH

As a whole students' experiences of mainstream school were characterised by 'academic mismatch'. This theme denotes the emergent tensions when individual factors such as ASD-specific characteristics, the students' academic abilities, learning styles and preferences interacted with school factors including the curriculum content, pedagogical and assessment practices. 'Academic mismatch' occurred when student factors interacted with school factors to generate restriction around capacity to participate. The points of mismatch differed across students and school contexts and students responded to the mismatch in different ways. Typically, from the perspective of students in this study 'academic mismatch' was experienced in two key areas: curriculum (sub-theme one) and tasks (sub-theme two).

8.1.1 Sub-theme one: Curriculum mismatch

Students reported experiencing curriculum mismatch in relation to: schoolwork performance; the content; how it was delivered and the settings in which it was delivered. Not all students experienced tensions in all of these areas and students reported tensions to varying degrees. This variance was due to differences in their personal and school contexts and the interactions between them. Three students experienced mismatch in relation to schoolwork performance. Mismatch was experienced in three aspects of the work: the quantity of work, the pacing of the work and the standard of the work. In all three cases there appeared to be a discrepancy between school

curriculum expectations, which are based on normative expectations for learning and achievement according to age and year level and the students' abilities and this produced a mismatch.

Luke experienced mismatch in relation to the amount of work in year nine. He reported feeling "intimidated" when he was presented with a lot of work. This mismatch appeared to stem from a difficulty with processing a large amount of information at once. He demonstrated an awareness of this difficulty and said it could be overcome if the information was presented in smaller chunks.

"...When you give me whole sheet of work I find it difficult but when you just fold it up, give me a section each, it makes it a whole lot easier" (Luke).

Jake's difficulty in year nine appeared to have been related to the pacing of work. There was a difference between the pace at which the work was being taught and the pace at which he learnt.

"It puts me under pressure having to keep up with the work... they kept going on ahead. You'd have to stay back and continuously keep on asking questions 'cause you didn't understand something" (Jake).

He demonstrated an awareness of his own capabilities when he reported that his learning would have been improved if his previous school had provided work that was commensurate with his level of ability.

"Different levels, like you might be in the same grade but people would have to be set work so they can understand" (Jake).

Declan reported that at his previous independent school he had felt under pressure to perform to their standard or face exclusion. This school appeared to have high expectations of their students in terms of academic achievement.

"They're trying to manufacture you to be an A student and turf you out so they get the good results for their school" (Declan).

In response to the mismatch experienced in relation to their schools' expectations about academic performance, Declan and Jake described the agentic strategies they used. Both described how they avoided doing schoolwork. For example, Jake reported that he used to get out of class by going to the special education unit. Similarly, Declan described himself as frequently "manipulating" his way out of doing work because he felt the workload was unmanageable and didn't match his ability, as it was too hard.

“Just the workload and whatnot...what they were asking of me was unreasonable. For what I could do and what they wanted me to do was completely off” (Declan).

It is unknown whether schools made accommodations for these students to try and increase their participation as staff members were not interviewed. However, the students reported that they had received little learning support. Due to feeling overwhelmed by the amount or the difficulty of schoolwork that they were expected to complete, the students often chose to avoid it altogether.

Declan and Jake both had disrupted trajectories. These trajectories were characterised by numerous suspensions from school and changes of school, which led to sustained disruptions to their participation. Consequently, both students reported that they were behind in their schoolwork. Jake said he had been “behind most of the time” and Declan said at his previous school he “wasn’t learning anything”. For these two students, their experiences of being ‘behind’ may have been the result of a cumulative effect of restricted participation over many years. However, as mentioned in the trajectory chapter, it was a turning point when Declan changed schools in year eleven as the school made adaptations to accommodate him. Declan’s comment below indicates that when offered support by his current school he was enabled to participate. Consequently he felt that he no longer had to avoid the work.

“I don’t really do it so much now. I don’t need to. ...There’s support, there’s good support. They want you to learn things but they want you to learn at your own pace. Not, they want you to learn to an A plus student standard [referring to previous school]” (Declan).

Rhys’s experience of schoolwork performance provides a contrast to the experience of the students discussed above. Although Rhys thought the workload in year nine “sucked” he said it was “manageable” and therefore was not a source of mismatch for him. He was attending accelerated classes for most of his subjects and was reportedly receiving almost straight A’s. He said that he often finished the work in class before his classmates. If he had schoolwork left to do he would finish it off in the special education room during lunchtimes. Rhys’s positive academic experience was facilitated by both his personal characteristics and school context. He did not appear to have any underlying learning difficulties; in fact he described himself as being intellectually “a step above a lot of the kids in the class”. He also described his school teachers as “accommodating”. This combination of factors may have contributed to his academic success. Further, he was one of the few students who had a ‘relatively stable participation trajectory’ and so unlike many of the other students interviewed he had not been disrupted academically over time. It could be interpreted

that he experienced cumulative advantage, in that his positive early experiences at school continue to be reinforced in later years.

The curriculum content could also generate areas of mismatch for students. For six students the mismatch stemmed from the expectation that they would participate in core subjects even though the students said they didn't "get" these subjects. Three reported difficulties with maths and three with English. They perceived that mastering these subjects was out of their control, despite taking deliberate actions to redress these difficulties. For example, a regular tutor had not altered Brad's experience of maths, while Brendan's perception was that despite years of assistance he was unable to improve in areas of English.

"I'm honestly in the lowest maths class, lowest level – key maths plus... I just don't know how to do it most of the time. Even though I get a maths tutor every Saturday" (Brad).

"It's just that I'm not good with spelling or adding grammar... I can't really get better at spelling, writing and grammar... I've had many help over the years but I haven't really got better" (Brendan).

It is possible that the students could have had underlying learning difficulties. Alternatively, another possibility is that the instructional and/or the assessment methods employed in these subjects did not match their unique learning styles. For example, in an interview with Brad's mother she reported that there is an expectation at his school that when completing a maths assessment students will document their working out. However, she reported that when Brad participated in a maths assessment he would write the answer to a sum down without documenting his working out. Consequently, he was marked incorrect even when the final answer was correct. Brad may not have realised that the teacher needed to understand how he arrived at his answer. This could indicate a Theory of Mind (ToM) difficulty or 'mind-blindness', which is common among people with ASD and involves an inability to recognise the thoughts, beliefs, intentions and desires of others (Baron-Cohen, 1997). English and maths are core subjects at school and students are usually required to be enrolled in them until year 12. Consequently, negative experiences in these areas could potentially impact on a student's participation experience more broadly.

Mismatch around curriculum content was not solely a result of the schools' expectation. It could also occur due to the student's personal beliefs about what the curriculum should include, or when personal expectations about particular content did not fit with the curriculum that was being

delivered. For example, Brad experienced some resistance due to his expectations of how science should be taught, while Brendan resisted the dance subject due to his belief that it was for girls.

“I don’t really like science as much as I thought I would ‘cause we’re not often doing experiments – we’re just writing about nature and that’s not really what you should be doing in science. That’s just not what I feel you should be doing in science” (Brad).

“On Mondays I refused to go to school because there was dance on Mondays...the dancing didn’t seem right to me. It was practically girl dance” (Brendan).

Most of the students expressed a preference for practical school subjects such as home economics, manual arts and computer education. Three students wanted schools to offer more subjects related to their interest in computers.

“I think there should be more subjects about computers I mean ‘cause technology is taking over the world currently” (Brendan).

“I like it when you learn about what you want to learn about...want to learn more about computer stuff. Thinking of being like a game designer or something like that” (Luke).

“The whole set up...it needs to cater to individual learning and what they want to do with their life, not what the school wants them to do with their life and what the school curriculum is set up for. For instance, there were no things at [previous school] for fixing computers so I was getting in trouble all the time for fixing computers and looking at them and whatnot” (Declan).

These personal preferences indicate an awareness of their own strengths, interests and personal learning styles. For example, two students said they learnt best through practical, hands-on activities, indicating a sound knowledge of their own learning styles. For Declan, practical subjects aligned with his tendency to learn by doing and if necessary, repeat the task, whereas Luke appreciated that in a practical subject such as industrial technology and design (ITD) he could produce a concrete product.

“I can’t learn theoretically. I need to be shown how to do something and then I do it and if it’s wrong, show me again and tell me what I did wrong and I’ll keep doing it until I get it right” (Declan).

“The ITD, like what I like about it is that you can actually have a... like you’re doing the making thing now so, what you can do is you can have an idea in your head and you just go ahead and make it” (Luke).

While mismatch between curriculum content and student interest may be commonplace for the general student population in secondary school, it seemed that the lack of congruence between the specific interests of students with ASD and the topics of their learning was particularly challenging for them. Three reported that if the work wasn’t of interest then there was “no point”. For example, Brad, who was one of these students said:

“I honestly can’t stand music ‘cause um I just don’t feel there is no point in doing it unless you sign up for it” (Brad).

It is possible that their motivation was embedded within their broader experiences as a student with a disability. Narrow interest areas are a core diagnostic feature of ASD (APA, 2013). It is possible that this characteristic reduces the willingness of students to engage in topics that are not of interest to them. This is supported by a previous study by Church et al. (2000) in which teachers and parents of students with ASD reported that one of the biggest challenges for them was finding ways to motivate the students to be interested in anything outside of their particular areas of interest. Declan suggested that getting disabled students interested in learning required greater effort and if successful could avoid problems.

“If you can get the students interested then you can get them to put effort in, you have a lot better results. Get a disabled student interested in something, they’ll want to do it, you won’t have to force them and spend heaps of time and effort trying to get them to do things like you do now” (Declan).

Additionally, Brendan indicated that adapting the work to the student’s interests might improve concentration.

“What helps me learn best is well if I can keep focussed and don’t drift off. Like if the work’s enjoyable and if it’s about computers then I tend to stay focussed” (Brendan).

It is recognised best practice in ASD education to incorporate the strengths and special interests of students with ASD into their curriculum (Charman et al., 2011). Furthermore, research suggests that utilising special interests can improve attention and task engagement (Boyd, Conroy, Mancel, Nakao & Alter, 2007).

It was also evident in many students' stories that the experiences of curriculum mismatch were often related to the way that the content was delivered and this in turn, influenced their participation experiences. Consequently, teachers were integral to participation experiences. The students' experiences of teachers can be described on a continuum from positive to negative. Rhys and Luke described all their teachers in positive terms such as 'nice', 'understanding' and 'accommodating'. Several others had mixed experiences of teachers, for example Beth said, "some of them were nice, some of them were mean". Jake was at the other end of the continuum as he perceived all of his teachers in a negative light. He said: "I hated a lot of the teachers there; I didn't like any of them".

Teachers could both reduce mismatch or conversely, be a source of mismatch. Students were positive about teachers who explained the schoolwork clearly and displayed authenticity by "actually listening" and "wanting to help" and answer their questions. They also valued teachers who got to know them as individuals, "treated everybody as an equal", and accommodated their differences. In these cases, it was apparent that a teacher could not only mediate potential mismatch, but also enhance participation, by taking a proactive approach. For example, Paul said his teacher had facilitated his learning by setting him work that he was interested in. This was also exemplified in Brad's situation where his year eight english teacher had incorporated his special interest into the daily class routine.

"We've gotten on pretty well since day one. Yeah in like term one and two we had this thing called 'Brad's quote of the day' when I said an interesting fact - all the other kids were really excited to hear it" (Brad).

Likewise, Rhys's experience was that his teacher was accommodating when setting assessment, which indicated to him an awareness of his unique needs.

"Yeah they're really good. They like help out cause they know my situation like going to AQ and that so they accommodate, they adjust assignments for me and all that so it's really good" (Rhys).

In some cases curriculum mismatch continued in spite of teachers' efforts to reduce it by offering help. Three students reported that they resisted help from their teachers. These students stated that they didn't ask for, or rejected help offered to them in the classroom. Their reasons for refusing help varied. For instance for Brad it related to his need for independence.

“Sometimes I just don’t understand what we’re meant to be doing and I often reject other teachers help ‘cause I want to do it myself” (Brad).

The help being offered may have reduced their difficulties and decreased the mismatch experienced. The impact of refusing/not asking for help was potentially negative in that the students said they had continued to struggle with the work. For instance Jake said: “I was behind most of the time, ‘cause I didn’t want to ask the teacher for anything”. In contrast, other students were willing to ask for help in class when they required it. These students may have recognised that asking for help had personal benefits for them in terms of improved learning and understanding and hence were motivated to do so. Therefore students’ perceptions of help was linked to acceptability.

According to the students’ reports, not all of their teachers were as accommodating of their special needs. Some teachers were actually perceived as being a source of mismatch. In these situations, it was evident that the student-teacher interaction was characterised by a struggle, which the students perceived to be related to their needs as a student with ASD. In Brad’s description of his experience in year five, it appeared that his struggle with the work tasks and his teacher’s tendency to “yell” daily at him were interrelated and a point of mismatch leading to the teacher ‘giving up’.

“Like in year five I had this teacher who was also really old school and his name was [teacher’s name] and he, and seriously every day he would yell at me, cause I was just really struggling that year and um I was thinking what’s the point in going to school it’s going to be, he’s just going to yell at me again and each day I was sent outside ...and another time he said “you know Brad, I give up on you”. Have you ever really heard of a teacher who is so fed up with one student that he gives up on them? ...I honestly felt kind of sad that he’d give up like that” (Brad).

Year five was the most challenging year of school for Brad due to the clash with his teacher. This year became a turning point in his participation trajectory, as it was when his mother said she recognised there were “issues” that she “needed to address” and she consequently sought a diagnosis for him.

Likewise, Declan described his experience of being “palmed off” at his previous school by his year ten english teacher. In contrast to Brad’s experience, the student-teacher struggle in Declan’s case was perceived to be due to the teacher’s incompetence and lack of interest in finding out the facts when things went wrong.

"My english teacher, she was completely incompetent...the way she handled me being with my circumstances I wouldn't even classify her as a teacher... she just tried palming me off to somebody else instead of say if I was doing something wrong in class, instead of investigating and making sure it was me, making sure I did that said thing, she'd just go 'you're banned', go to the computer guy and say 'take his computers away' instead of looking at it in a reasonable manner and saying well 'did you do it?' 'No, I didn't do it', 'fair enough' but she just went on the assumption I did, so didn't get any computers" [voice quivery and upset] (Declan).

As a result he avoided her and by doing so, missed out on participating in this aspect of the curriculum altogether. However, it is noteworthy that he took this action even though he perceived that the problem was related to the teacher's limitations. In this case, Declan also believed that he was "very close to getting turfed out" of the school altogether. It is likely that Declan considered that not going to class was his only choice to avoid getting into further trouble.

"I wasn't going to her class anymore because of her sheer stupidity and whatnot...I just stopped going because she was getting me in so much trouble" (Declan).

One explanation for the variation in teachers within and across the schools relates to attitudes. Not all teachers may have cared and been willing to make accommodations for students with ASD, as they may have perceived it was not their responsibility to do so. Several studies of teachers experiences of including students with ASD have found that teachers took less responsibility for the children with ASD in their classroom because of the presence of a teacher aide and consequently teacher aides worked primarily with the children with ASD and the teachers sometimes had little involvement or direct communication with the student (Emam & Farrell, 2009; Humphrey & Lewis, 2008a). However, in this study structural factors may have also impacted on teachers' classroom practices. Even teachers who have positive attitudes towards students with ASD and who are committed to their inclusion face challenges such as negative school cultures, large class sizes, limited resources and time pressure which make it difficult to make individual adaptations (Emam & Farell, 2009). Furthermore, students with ASD have highly idiosyncratic learning needs and they change over time (Jordan, 2005). Teachers may not have had ASD-specific training (Barnard et al., 2002) and therefore may feel they do not have the skills teach children with ASD (Humphrey & Symes, 2011).

The physical settings in which students were taught the curriculum impacted on their participation in it. The mainstream classroom was one such setting. The loud noise level in mainstream

classrooms was a source of mismatch for six students. These students may have had sensitivity to noise in the classroom related to their ASD and had difficulty filtering it out (Ashburner et al., 2008). Loud noise may have triggered these sensory sensitivities and impacted on concentration. For example, Luke reported it was difficult to remain on task and complete the work: “I can’t focus on my work so it just makes a lot more difficult to get through”. Jake’s quote indicates that there seemed to be a threshold at which noise became a source of mismatch for him.

“I can usually cope with noise if it’s moderate, I wouldn’t go to extremes, if it gets really loud I would just cover my ears I guess” (Jake).

Peers and teachers who “yelled at the class” were the most commonly identified sources of noise that created a distraction from the task as Rhys illustrated.

“Quite a few of them can be annoying a little bit. Like they’re just loud and disruptive a little bit... I just can’t really concentrate that well” (Rhys).

These sources of noise may have been unpredictable and this may have been distracting for students. This is supported by a quote from Luke in which he indicated that noise was not a distraction for him if it was predictable.

“When in ITD that’s the loudest class, but I don’t mind the noise there ‘cause you know it’s gonna be there... it is a workshop after all” (Luke).

Problems with attention and concentration due to noisy classroom environments may have been compounded if students also had underlying attention deficits, which are commonly associated with ASD (Ames & White, 2011; Mayes, Calhoun, Mayes & Molitoris, 2012).

Students described both their teachers and their own attempts to control the noise level in the classroom environment. Two students described situations in which their teachers had asked the other students in their classes to be quiet; however, students reported this was rarely successful. Two students attempted to manage the impact of noise on their participation themselves. Brad reported that he told his peers to “shut up” when they were being loud, whereas Luke reported that he found a quiet spot outside the classroom. These personal actions to some extent indicate the students’ attempts to use agency to control and enhance their participation. Interestingly, while Brad tried to control the situation from within the classroom without much success, Luke opted to remove himself to take some control from outside the classroom.

“I said “shut up, that’s a really... that’s a terrible song” and um they just keep doing it. Eventually they laid off” (Brad).

“Just see if I get a spot outside the classroom, because we’re in like a little pod where there’s desks in the middle inside the building so all the classrooms are surrounding the middle so I can see if I can get a spot out there... generally it’s quieter out there so it helps me concentrate” (Luke).

The findings of this study in relation to the physical environment at school and its impact on student participation are comparable with the extant literature. Ashburner et al. (2008) found that auditory filtering difficulties were significantly negatively associated with academic performance and attention to cognitive tasks and appeared to contribute significantly to academic underachievement. Furthermore, Saggers et al. (2011) reported that more than a third of the students with ASD reported that concentration on their work was hampered by noise and several also reported difficulties with teachers who yelled.

Special educational settings were also a source of mismatch for three students. This was not due to environmental features in these settings, but rather because they missed out on mainstream content when attending special education settings. Most of the students currently accessed, or had previously accessed specialist curriculum support from the Special Education Unit (SEU) in their mainstream schools. For example, at her previous private school Beth attended one social skills class per week in the SEU and this meant “missing out” on mainstream curriculum content.

“I would have to go up to the O Block every Thursday for one of my whole lessons so I was like ‘that’s annoying’...because I didn’t like going up to O Block cause it was boring...because I missed out on a lot of important things for my assignments and a lot of time to research and stuff” (Beth).

Seven of the eight students attended or had previously attended an AQ placement off campus for part of their school week. Brendan and Rhys reported that attending this setting led to them “missing out” on curriculum content in the mainstream school. “Missing out” was a double edged-sword. It simultaneously created and reduced potential mismatch as this quote from Brendan illustrates.

“Well having to go to school for two days, go to high school two days a week I do miss out on a lot of subjects...I think it’s kind of nice I get to miss out on subjects I don’t want to do but there’s also subjects I do want to do that are on the days that I’m not there” (Brendan).

These students felt they missed out on participating in the mainstream context as they missed curriculum content in specific classes when being withdrawn for specialist help; however students reported good participation in the AQ context. They felt their teachers were invested in developing a personal relationship, in understanding them and their individual interests as Rhys described:

“They’re definitely the best. They’re really, really good, they’re understanding and that. They really get to know you personally which is good... you’re not just like another kid. He gets to know your personality and that and treats each of you differently according to that” (Rhys).

Students varied in their perceptions of the schoolwork offered at AQ. For example, Jake felt it was beneficial to be able to complete schoolwork at his own pace: “They roll along with you...they actually want to help”. In contrast, Beth perceived the schoolwork was not commensurate to her ability:

“I didn’t like it because like all the work the teacher would give me like the main teacher would give us was for like grade 2 ‘ers. She’d give us things that said like 2 + 4. I’d finish it in like 2 minutes or a minute” (Beth).

These examples highlight the heterogeneity among the students with ASD in this study and the need for curriculum to be tailored to their individual academic abilities.

8.1.2 Sub-theme two: Task mismatch

Specific tasks related to the curriculum were another source of ‘academic mismatch’. Difficulties were reported with oral assessments, handwriting and homework. Some students experienced difficulties in all three areas, whereas others experienced difficulty with one. Mismatch occurred when personal factors (for example, child’s impairment in motor skills) interfered with completion of a particular task (for example, handwriting) generating restricted participation. Students were keenly aware of this and expressed stress and frustration. In limited instances they reported that their teachers, for example during oral assessments, accommodated their difficulties.

Rhys and Declan reported they found it stressful to do oral presentations in front of their peers during class time but did not elaborate as to the reasons. One explanation is that there were

underlying difficulties with communication and/or anxiety due to their ASD and this may have impacted on their capacity to successfully complete the task. This may have been further intensified by features of their classroom environments, such as the noise created by peers. Both were given the option at their schools to present oral assessment privately for their teachers outside of class time. They both reported this was less stressful for them; however they said the stress of doing oral assessments was not entirely removed.

“In that environment definitely, it’s a lot easier. Even then I still get pretty nervous but it’s definitely not as bad” (Rhys).

Beth, Declan and Jake reported that handwriting was a particular difficulty for them. Their preferences were to use computers rather than to engage in handwriting for schoolwork. The difficulty centred on the tension between task expectations and functional ability. In turn, this shaped their participation in the curriculum. This quote from Declan illustrates the tensions that can emerge between the task expectation such as writing on the one hand, and personal factors on the other, which he described as an “ill-used hand”. Declan had a longstanding difficulty with handwriting which he attributed to fine motor problems.

“I don’t do anything to do with writing. I’m just trying to commit it to memory. It’s working so far, not well but it’s enough...I can’t, it’s not something I do. Not even something I did at my previous school. Just because I’m at a new school doesn’t mean I’m going to turn over a new leaf and start using an ill-used hand that has muscles or whatnot and cramps up after like two sentences. It’s not going to miraculously get better and I can write paragraphs” (Declan).

The extent to which early schooling experiences contributed to these tensions for Declan is unknown. However, Declan’s mother stated in her interview that in early primary school a teacher had scrunched up his schoolwork and thrown it in the bin, as it was “illegible”. Her perception was that this experience directly led to his refusal to do handwriting from an early age illustrating cumulative negative influences. Interestingly, as the extract above indicates, although Declan perceived a loss of control due to his fine motor restrictions, he did seem to exercise some agency in trying to commit things to memory to compensate and was aware of the limitations of this decision.

Two prior studies of students with ASD attending mainstream schools have reported similar results in regard to handwriting. In both studies students with ASD reported handwriting to be physically demanding and exhausting and that it negatively impacted on their school participation (Church et

al., 2000; Saggers et al., 2011). Furthermore, a review of the existing literature by Kushki, Chau & Anagnostou (2011) found that the current evidence suggests children with ASD have diminished overall legibility in handwriting and that impairments in fine motor control are a likely contributor to handwriting difficulties.

Six of the students in this study reported difficulties with homework. The other two students reported that their teachers did not give them homework. Students reported a range of difficulties with homework including: trouble getting started and then remaining on task if it was a long assignment; leaving it until the last minute; not getting it done on time or at all. These difficulties could be attributable to problems with attention and executive function such as organisational issues, which are associated with ASD (Zingerevich & LaVesser, 2009). They could also be related to motivation as is indicated below in an excerpt from Luke.

“When it’s a really long homework like an assignment, after getting started it’s the, when it’s an assignment it just drags on and on and on and you’re just like ‘oh I just can’t do this anymore’” (Luke).

All of the students reported disliking homework and several refused to do it. Jake’s comments about homework revealed he believed that school is the place for academic work, not home. This led to him resisting doing homework even though he experienced negative consequences for not doing it such as “being yelled at” by teachers and receiving detentions.

“I didn’t like the idea of it. I thought it was pointless...we’re already doing homework during school so why do we have to take work home?” (Jake).

Although all of the students said they did not like homework and most had difficulties with it, half reportedly still did their homework. This variability could relate to individual differences in motivation and capacity for flexible thinking. On the other hand, it could relate to the homework content and amount of homework they were given, the level of difficulty and support the students received from parents to complete their homework. For instance, Luke had previously not done his homework but was now successfully completing it after being given a homework checklist by his mother to use each afternoon. This “helped him get organised”. He was also required to hand it in to a teacher the next morning.

“My mother gives me a note every morning which I go to get signed because I used to have a bit of trouble with homework, you know getting it done and all that, so I have to put in a note with my homework attached everyday – make sure it gets handed in” (Luke).

This example also implicates the idea of linked lives. It shows how the link between student, parent and school can be positively activated to redress potential inhibitors of participation. In this case, Luke's mother and teacher formalised a process to ensure Luke was supported to complete his homework tasks.

8.2 THEME TWO: STANDING OUT

The second dominant theme was 'standing out'. It involved an experience of being different from their mainstream peers and not fitting in at school. Primarily standing out was experienced during social interactions with peers in the playground (sub-theme one). However, there were some examples of 'standing out' during class time (sub-theme two). The experience of 'standing out' differed across students. Students also varied in the way they responded to it. Friendships appeared to act as a buffer to 'standing out' for some students. Students' experience of 'standing out' appeared to be influenced by the broader school culture, which varied from school to school. The following excerpt from Rhys illustrates the overall theme of 'standing out': "I feel like I don't really fit in that much".

8.2.1 Sub-theme one: Standing out in the playground

Six of the students perceived that they stood out in social spaces at school such as in the playground. The physical design of space and the activities that occurred within that space influenced how they participated in the space. The students described the break time spaces in secondary schools as being open spaces with no playground equipment, an oval and often there were handballs courts. A narrow range of activities occurred in these physical spaces. The students stated that their mainstream peers spent the break times either talking with one another or playing handball or other sports. Talking was the primary activity and this was a barrier for some students since their conversational skills varied. Brendan said he enjoyed talking with friends during breaks in their spot behind the tree, whereas several other students described their difficulties with aspects of social interaction and conversation. Rhys had difficulty contributing to lunchtime conversation. In particular it appears that he had difficulty understanding the etiquette of group conversation and consequently was deterred from participating in it.

"Like I can't really just, I don't really get into it that much, like I don't really understand it too well. Yeah ...I don't really go out now. 'Cause I used to just stand around in a group and I'd never really say anything, I'd just I guess I'd just be there, there wasn't really a point in that" (Rhys).

Similarly, Beth recalled an instance in which she had misunderstood a peer during a social interaction. This led her to have a “meltdown”.

“My sister’s boyfriend was joking around and he screamed at me, like he was like ‘stop yelling at me’ (yells) and I ran off and had a meltdown... cause I didn’t know he was joking around with me at that point” (Beth).

Three students indicated that there were “set spots” where mainstream peers sat during break times and that these peers had claimed ownership of these spaces. Therefore not all spaces were communal. For instance, Luke described an occasion on which he had attempted to enter a set spot to which he did not belong and was ostracised by his peers. Luke’s quote indicates there was etiquette around the spaces where students could and could not go at his school. He was aware of this and accessed the oval as “anybody” could go there. This strategy may have prevented further ostracism.

“Set spots, you try to go over there you get kicked out...there’s only one place other than the computer room that I’m accepted and that’s down just in front of the oval over at the handball courts, there’s a little square for handball. That’s basically anybody goes there” (Luke).

Seven of the eight students reported that they were different to their mainstream peers in terms of the spaces they occupied. They spent much of their time alone and away from the most widely used break time spaces. They described walking around by themselves or spending break times in spaces they identified as “refuges” such as the library, computer room or the special education unit where they could get away from the “big crowd” of mainstream peers. The students had an awareness of their differences and attempted to camouflage these differences by accessing “refuges”. The following excerpts demonstrate that the intention of this was to minimise negative attention from their peers.

“During lunchtime ‘cause I don’t like to do, I don’t like to do what most of the other kids like to. So I just go to the library ‘cause no one questions anything” (Brad).

“You make sure, not stay hidden, but like keep quiet so no one notices you that much, that’s what I try to do” (Rhys).

At times solitude was actively favoured in order to spend time engaging in preferred interests, to process the events of the day and to de-stress. This excerpt from Rhys sheds light on his rationale

for choosing solitude - it appeared to provide him with a non-judgmental space in which he could process his thoughts.

“I prefer it usually. Of course talking to people and that is good but usually I prefer to be by myself. I don’t know, I guess you just don’t have to deal with everyone else, like deal with other people and that and worrying about like other people judging you and your opinions and that. There’s no one around to like really judge, it’s just yourself I guess and it gives you time to think and that. It gives you time to do what you want instead of focussing like on other people and that” (Rhys).

While many of the students reported that they sometimes enjoyed spending break times alone pursuing their interests, most also expressed a desire to spend some break times with their mainstream peers. However, they experienced rejection from their peers. For instance, Jake said: “It’s just: you’re a dick, go away”. This reinforced their solitude. This is exemplified in the quote below from Declan in which he described being made to feel like “an outsider” at his previous school by his peers and in response he isolated himself. Therefore, not all solitude was self-initiated; sometimes it occurred as a consequence of peer rejection.

“I actually separated myself and they kept treating me the same way and I’m like ‘I don’t care; I’m not going to talk to you anymore’ ” (Declan).

Students perceived they were targeted by their peers for ‘standing out’. As reported in the analysis of parents’ perceptions of schooling across the years, bullying was universally experienced by the students. It manifested in a number of ways. Half of the students described being labelled by their peers. Labels included “SPED” and “weirdo”. The labelling process seemed to involve a whole person formulation as ‘other’ or ‘deviant’ which deterred peers from getting to know the student as a person. For example, Luke said his peers treated him like “an idiot” when he wasn’t. He felt he was stigmatised by his peers due to his involvement in the Special Education Class (SEC).

“...When you’re in a high school as soon as people find out you’re in the SEC a big target is painted on you... because people in the SEC they generally associate it to ADHD, ASD and all that” (Luke).

Interestingly, half of the students in this study labelled their mainstream peers with terms such as: “idiots and morons”, “naughty kids” and “snobs”. In some cases this appeared to be a defensive response in order to cope with being labelled and stigmatised in the first place. However, not all of the students who labelled their peers had been labelled by them first. In these examples, it was

possible that labels were related to students with ASD having their own particular standards of behaviour and evaluating their peers against these standards. This is exemplified in this comment by Jake:

“Well I wouldn’t personally like them, like I said I only like people that are down to earth; a lot of them are faggots, not faggots just stupid... the way they go around acting like they’re tough shit on top of everything, yeah those were the people I really hated” (Jake).

Other forms of bullying were also reported. All of the students reported being teased by their peers. For three students teasing was not only in relation to their ASD, but to other differences that made them stand out as well. For example, Beth and Rhys reported being teased for being overweight. Half of the students also described being provoked by mainstream peers with the intent of getting them into trouble. Two students gave examples of mainstream peers destroying their personal property. In addition, two students described being physically assaulted by their mainstream peers. The quotes below are illustrative of the various types of bullying experienced by students.

“...A lot of people tease me about my size” (Rhys).

“Like she would be like she’d get me into trouble, she got me sent to the principal’s office because of that, because of something that I didn’t do” (Beth).

“I just wish that people wouldn’t, would just stop sabotaging my work! ...Like last, a couple of weeks ago, took out my work, there was all over the top glue with nails in it” (Luke).

“Someone hit me in the head with a glass bottle and I got knocked out” (Paul).

Bullying was rarely a one-off experience, rather it was a sustained experience across schooling years and contexts. The students reported experiencing bullying at their previous schools and six of the eight were experiencing bullying in their current school at the time of their interview. Bullying impacted negatively on the students as evidenced by expressions of anger, sadness and loneliness during the interviews. Half of the students stated that the worst thing about school was the social aspect of it and coping with bullying in particular. For example, Luke said: “the worst part is having to deal with people teasing you every day”.

The students had different explanations as to the reason they were bullied. Comments from three students suggested there were social status hierarchies operating in their schools. For example, Jake said:

"I'd be teased 'cause there's always grades of people, there'd be the losers going up to poppies" (Jake).

Jake's comment indicates that he had low status within the social hierarchy of his school and he was targeted as a result. Three students attributed the cause of bullying to their peers' lack of understanding of ASD. For example, Rhys felt his peers had little understanding of how his ASD manifested.

"A lot of them don't really understand autism though. Like they don't understand why I like shy away and all that stuff and why I'm not very good at taking jokes and all that. Like jokes aimed at my expense. Yeah, they don't really understand it that much. Like if I told them I was autistic they'd ask "what is that?" Like they've never heard of it and all that" (Rhys).

Notably, the students often reacted to the bullying they experienced and these reactions varied across the students. For example, Luke attempted to resolve the bullying. He described using a combination of strategies - trying to be friendly, asking the bullies to stop and ignoring the teasing. He reported these strategies were unsuccessful and that the bullying continued. This indicates he had little personal control over the bullying. He also engaged in physical fights. This response seemed to occur after other strategies such as ignoring had proved ineffective. He perceived he had little control over his own emotional and behavioural reactions.

"Mostly try to ignore them but it gets too much (frowns) just can't help it; not physically but verbally fight back, unless it gets extremely annoying, then just can't control myself and it [a physical fight] happens" (Luke).

However, Luke reported that his ability to regulate his emotions when interacting with peers had recently improved since his mother had changed his diet.

"Lately we've been going on a diet... that's really helped actually. I used to be able to not like, just one insult and I'm straight to the stage where I just want to hit somebody, but it's actually gotten a lot better...generally find it easier to cope with" (Luke).

This exemplifies the idea of linked lives, in this case both between a student and their parent and between the home and school contexts. It demonstrates how a parent intervention at home (in this case changing Luke's diet) improved his participation experience with his peers at school.

Five of the other students reported that at times they had responded to bullying by fighting back. For Jake this had involved bringing a knife to school and at other times he had carried around a

stick because he felt unsafe. Declan had responded by provoking his peers.

“They were bullying people and they were trying to bully me and I just got sick of it and I started yeah just trying to annoy them and get them in trouble, ended up getting me in trouble” (Declan).

This excerpt indicates how Declan’s ongoing experience of bullying led to him becoming a ‘bully-victim’ - that is a target and perpetrator of bullying (Chen & Schwartz, 2012).

In most cases students’ responses to bullying led to them “getting into trouble” for fighting which was against the school rules. These students reported that they had been in trouble repeatedly over the course of their schooling as the extract from Brendan illustrates.

“I’ve been in trouble a few times at school...there has been a few times where I’ve gotten into fights, that I’ve gotten into a fight because someone provoked me” (Brendan).

Rhys was one of two students who had not engaged in physical fights. He reported that he had not been in trouble: “Nah, I generally try and keep away like from all the activity I guess”. This quote indicates that he recognised peers were a source of potential trouble and so he avoided them. This agentic strategy was effective in the sense that he did not get in trouble at school but it isolated him from his peers and thus restricted his social participation. It is important to note that Rhys had also been rejected by his peers, and so he wasn’t freely choosing solitude. This indicates there was a complex and interdependent relationship between him and his peers.

From the students’ reports it was also evident that schools typically used suspension in response to bullying incidents. Half the students in this study reported that suspensions were a frequent occurrence over the course of their schooling. Unsurprisingly, these students were represented by the disrupted trajectory pattern. It was evident from their parent’s reports that numerous suspensions negatively impacted on their participation. Students missed out on large portions of school, which is likely to have impacted negatively on academic achievement.

The repeated use of suspensions suggests that other possible reasons underpinning the bullying may not have been considered. Rather than examining the broader social context, the problem therefore appears to have been attributed solely to the issues of the students with ASD. This phenomenon could be interpreted as victim blaming. This finding is consistent with previous research by Starr et al. (2006) who found that 37.5% of the students with ASD had been suspended and that significant

negative correlations existed between school suspensions and teacher's ability to determine the cause of behaviour.

There was one example of a staff member intervening in a positive way to reduce bullying. Luke reported that his teacher had addressed bullying through educating his physical education class about ASD.

"The only teacher that I've had who actually stood up to the bullying was my PE teacher last year. He actually, I think it was in term two or three, he actually put me all the way over there (gestures far away) like at the other end of the oval, got the rest of them together, gave them a talk and surprisingly when I came back everyone's cool with me...so it's like he got them to understand me more" (Luke).

Three students wanted school-wide interventions to address the bullying in their schools, suggesting that they perceived they had limited capacity to exert influence over their environment.

Consequently, students suggested that changes to school bullying policies were needed. The majority felt their peers should be educated by their school about ASD to increase their understanding and in turn their acceptance of it. For example, Rhys' quote indicates that he felt it would result in students with ASD being treated as "normal" people rather than being rejected for their differences.

"If people understood more I guess like not teachers, more so students and that. Like they understand like instead of I don't know like um just basically if they treated you... (Deep breath) basically if they like treated you like a normal person I guess instead of isolating you because you look different and weird and that. I guess just I don't know people being more understanding in general like the kids and that there, it would be better if they were like a lot more aware of autism and other stuff like that so they can understand why you're different instead of just getting rid of you because you are different" (Rhys).

Students' reports about the bullying experienced at school are consistent with both their parents' reports and previous research. Several other studies on students with ASD attending mainstream schools found that the majority, if not all of their participants experienced bullying (Carrington et al., 2003; Hay & Winn, 2005; Humphrey & Lewis, 2008; Rowley et al., 2012; Saggers et al., 2011). Furthermore, previous studies have also reported that students with ASD experience bullying over time. Cappadocia et al. (2012) studied the bullying experiences of students with ASD based on the reports of 192 parents and found that many of the children with ASD were victimised frequently

and chronically over large periods of time. Similarly, Humphrey and Lewis (2008) studied the mainstream schooling experiences of 20 students with ASD from students' perspectives and reported that the students in their research experienced bullying with alarming regularity.

Frequent victimisation impacts negatively on children's self-concepts and this can lead to mental health problems. Cappadocia et al. (2012) found it was associated with mental health problems such as anxiety, hyperactivity, self-injurious and stereotypic behaviours, and over sensitivity. Portaway and Johnson (2003) interviewed 18 young adults with ASD and the majority of the participants reported that they had experienced enduring problems with anxiety, depression and/or obsessive-compulsive behaviours. There is a bidirectional relationship between bullying and mental health problems (Fekkes et al., 2006). Longitudinal survey research by Fekkes et al. (2006) with 1118 typically developing children found that children who were consistently bullied by peers had a higher risk of developing new mental health symptoms within the 12-month study period, and children who reported higher levels of mental health problems than peers had a higher likelihood of being bullied within the 12-month period.

In contrast to the experience of being targeted because of their difference, half of the students also reported a perception that they were invisible to some of their peers. For example Beth said of her peers: "they act like I don't exist". Feelings of invisibility also occurred beyond the classroom for Beth. She described being ostracised by girls in her neighbourhood and members of her youth group who also treated her like she "didn't exist". Students apparent invisibility at school may have been a consequence of them spending the majority of break times away from the communal space in "refuges" as it literally made them less visible to their peers.

8.2.2 Sub-theme two: Standing out during class

'Standing out' during class time was only briefly discussed by students, but still warrants discussion as it provides insight into their social experiences within the classroom. Three students stated that they didn't like it when their peers singled them out in the classroom for being different. For example, Brad described being impersonated by his peers during class.

"They just like made weird noises and when I was sitting on the other side of the room from them one of them was impersonating everything I did, that was just really annoying" (Brad).

Rhys reported being teased for not doing oral presentations in front of the class like his peers did and Beth expressed dislike for academic modifications that made her stand out. Her mother had given her a colour-coded library bag for each subject to assist her to organise herself between

classes. Her excerpt indicates she was aware that this was not age-appropriate for her as she was in year eight and this discrepancy caused her embarrassment.

“I had to have folders and books and stuff - oh gosh it was annoying ‘cause mum would put them all in like preppy library bags so I was like ‘embarrassing’” (Beth).

Peers reaction to disability supports such as teacher aides appeared to influence the students' perceptions about this type of support. Beth exemplifies this in the following quote:

“Everyone would just turn around and stare at us like [does patronising facial expression] ... like Megan would turn around and be like ‘ha-ha’ and I’d be like ‘grrr’” (Beth).

Whereas Luke spoke positively about having a teacher aide and said his peers found it beneficial too because they could access help.

“...Even some people who aren’t in the SCC [self-contained classroom] they can get help too so they find it a bit good for them too so they don’t really mind” (Luke).

The findings in relation to teacher aides are comparable to previous studies. Research by Diez (2010) about the school experiences of 48 young people at risk of exclusion from their own perspectives found that nine young people with disability experienced specialist support as a ‘double-edged sword’ - on the one hand it was a source of recognition and help, and on the other it was a source of stigmatisation and marginalisation. Furthermore, in a number of studies involving students with ASD some of the students reported a dislike of being singled out for support as it highlighted their differences to their peers (Hay & Winn, 2005; Humphrey & Lewis, 2008; Saggers et al., 2011).

Despite all of the students in this study having negative experiences with some of their peers most students identified peers who were their friends. There were similarities in the way in which the students described their friends. Friends were peers with whom the students talked to, got along with and who shared similar interests such as computers and video games. They had personal qualities such as being “nice”, “down to earth” and “understanding”.

The number of friendships varied, as did the amount of time the students in this study spent with friends at school. Two students reported that they had “no friends”, despite a desire for friends. Adolescent friendships are complex and require sophisticated social skills (Peterson, 2010) and it is probable that these students had social skills difficulties, which by definition are a core feature of

ASD (APA, 2013). Additionally, they were both in school contexts that appeared to have closed peer cultures, which may have been a further obstacle to forming friendships. In contrast, four students reported that they had a friend or two that they spent some of their break times with. The remaining two students, Brendan and Declan, were at the other end of the continuum in that they both reported that they had a group of friends with whom they spent their break times. They both had recently changed schools and since moving they had developed a group of friends. They were no longer ‘standing out’ and experiencing bullying. Therefore, friendships seemed to act as a buffer against standing out for them. This is exemplified in the following quote from Declan in which he reported fitting in at his new school.

“I do now, didn’t at [previous school name] but I feel I’m fitting in a lot better now...people are so much nicer... I have a place with people I sit with” (Declan).

Although this finding does not indicate a certain causal relationship, previous research by Humphrey and Symes (2010) suggests a link between peer support and reduced bullying. In their study in which a questionnaire about perceived levels of social support was administered to 40 students with ASD, 40 students with dyslexia and a reference group of 40 students with no identified special educational needs, it was found that support from peers successfully predicted reduced bullying for all students.

All of the students in this study desired and valued relationships with their peers emphasising the importance of linked lives. Half of these spontaneously identified friendships with peers as the best part of their school experience. For two students, friendships were the only positive aspect of school, as is illustrated by their quotes below.

“Probably just the friends that you meet at school, anything above that no” (Jake).

“Just seeing my friends but other than that there’s not you know, maybe seeing some people but other than that I just don’t like it. It’s just boring constantly, you know just sitting there just waiting till it’s over” (Brad).

There was incongruity between the desire for social relationships and the actual experience of most students. Although two students had a group of friends, the rest were not embedded in a social network with peers and their experience was one of isolation from their mainstream peers.

While the majority of students in this study reported having at least one friend they did not describe the quality or depth of these friendships. In previous research by Church et al. (2000) parents

reported that the friendships of their children with ASD in their study were often superficial. Furthermore, the findings from numerous studies in the United States using social network methods suggest adolescents with ASD have significantly poorer friendship quality in terms of companionship, security and helpfulness and smaller social networks (Wainscot et al., 2008) with lower social network centrality than their typically developing peers. They also experience less reciprocity in their friendship nominations (Bauminger & Kasari, 2000; Chamberlain et al., 2007; Kasari et al., 2011; Locke et al., 2010). Based on this body of research it could be inferred that some of the friendships of the students in the current study may have been superficial and/or may not have been reciprocated. This is supported by the fact that most of the students' parents reported their children did not have friends. However, the discrepancy between student and parent reports in this study could simply reflect differences in their conceptualisations of friendship.

Although the students in this research did not directly discuss difficulties with making friends, they described challenges in making conversation, which is a requisite skill for making friends. Furthermore, in two previous qualitative studies with adolescents with ASD participants reported challenges in establishing friendships (Carrington & Graham, 2001; Daniel & Billingsley, 2010).

Students' experiences of 'standing out' appeared to be shaped by the broader school culture, which varied from school to school. For example, based on their reports Declan and Brendan were currently attending schools that appeared to have a peer culture characterised by openness to difference and in these contexts the students felt welcome and accepted as part of the school community. However, this was not the case at their previous schools as Declan's comment illustrates: "I do now, I didn't at [previous school name] but I feel I'm fitting in a lot better now". The remaining six students were currently or had previously attended (for those that were no longer enrolled in school) mainstream schools that seemed to value conformity to 'normality' and in these school contexts students described being labelled, rejected and bullied by their mainstream peers because of their differences. This occurred in state, independent and catholic school contexts. These two excerpts highlight the differences in peer culture across the schools. Declan, described the openness of his peers at his current state school as opposed to his previous independent school.

"They're welcoming - like try to get to know me. Whereas if a new person came to [previous school name] they'd be suspicious and they'd be I guess bullying them because of the fact that we're in grade 11 and there's a new kid coming in - make him feel like an outsider"
(Declan).

In contrast, Rhys described the closed peer culture at his state school in which conforming to ‘normal’ was valued by his peers and difference was primarily perceived to be negative because it deviated from the accepted ‘normal’. Thus Rhys perceived he stood out as he deviated from the accepted norms of his school.

“The social aspect of it- the conformity basically, like you’ve got to be a certain way to be accepted into the society I guess of school which is pretty annoying considering” (Rhys).

Rhys’s perception of himself was not formed independently from his social world; rather it was influenced by his interaction with peers’ and their perception of him during these interactions. Charles Horton Cooley called this the ‘looking-glass self’ stating that people form their self-concepts based on their interpersonal interactions and their understanding of how others perceive them (McIntyre, 2006). Individuals with ASD can have difficulty understanding the mental states of others (Baron-Cohen, 1997), however Rhys demonstrated a high level of understanding of the perspectives of others during his interview.

In contrast to the ‘standing out’ experienced in mainstream schools, five of the seven students who had attended AQ reported fitting in with their peers there as illustrated by Luke:

“Just being in a group of people that are in the same boat as me, it’s just quite easy to get along with them. Like once you’re at AQ you are friends with everybody” (Luke).

For these students a sense of fitting in appeared to be fostered by the perception of shared common traits with peers i.e. ASD. However, the two remaining students perceived they were different to their peers with ASD at AQ and were unsure how to relate to them as Rhys described:

“It’s hard like, it’s kind of funny when you look at them and I don’t know like think that you can be that way with other people I guess. I don’t know, yeah like I don’t know it’s kind of hard to remind yourself that they have the same condition as you I guess” (Rhys).

This comment from Rhys indicates that he did not perceive he shared common traits with his peers with ASD and highlights the heterogeneity of the students with ASD in this study.

8.3 CHAPTER SUMMARY

Students in this study experienced ‘academic mismatch’ and ‘standing out’ in mainstream schools. The manner in which students experienced these phenomena varied due to differences in both individual and school contexts. The participation of students either increased or decreased,

depending on how these contexts interacted. For example, Declan reported that in his current school they were welcoming and made academic accommodations for him. Consequently, he reported that he was motivated and was “doing more work” and felt he fitted in with peers. Thus, his experiences of ‘academic mismatch’ and ‘standing out’ were minimised.

Students experienced mismatch in relation to academic participation. They experienced this to varying degrees in relation to aspects of the curriculum such as the content and in related tasks such as homework. Mismatch appeared to be the result of an incongruity between students’ underlying ASD-characteristics, individual preferences and abilities and features of their school contexts. Facilitating participation therefore requires a match between student characteristics and the school environment. This student-environment interaction can be understood by employing the Person-Environment-Occupation (PEO) model (Law, Cooper, Strong, Stewart, Rigby et al., 1996). The PEO model acknowledges the dynamic interplay between the person, the environment, and occupation over time. The fit between these three components may increase or decrease over time. It is proposed that close fit or overlap of these three components produces greater harmony in their interaction (Law et al., 1996). In contrast, where these components do not overlap, there is poor fit, generating restricted participation. An example of poor fit in this study is apparent in relation to handwriting. When student factors, (e.g. the child’s impairment in motor skills) were not accommodated by the school, (e.g. through supplying a laptop), this interfered with their completion of the task (handwriting) and led to restricted participation.

Students actively resisted and shaped their own participation within mainstream schools by exercising their agency. For example, some reported that they responded to ‘academic mismatch’ by refusing to participate in certain tasks or by avoiding certain classes. Refusing or avoiding certain tasks limited their participation. This interpretation assumes that participation was their goal but they might have had a different objective, for example to avoid personal discomfort rather than to participate. Some of their choices may prove to be maladaptive in the long term if they mean they continue to miss out on instruction and fall further behind academically. Research on typically developing students who have been excluded from school indicates that poor academic progress leads to a further reduction in self-esteem (Castle & Parsons, 1997; Hayden, 1997), negative perceptions by others of their capabilities and reduces their opportunities in the long-term to participate in tertiary education and employment opportunities (Daniels & Cole, 2010).

While students were able to exercise some level of agency in relation to their participation, their agency was restricted by their school contexts. Students provided few examples of accommodations made in their schools to support their individual learning needs and preferences, which suggests that schools may be rigid in their implementation of the curriculum and their expectations of students. Sainsbury (2000), an author with Asperger's syndrome, purports that mainstream classes are specifically structured to meet the learning needs of students who learn in a neurotypical way. She describes mainstream schools as "normalstream" because she considers them to be inaccessible for students with ASD (Sainsbury, 2000). Specialists in the ASD field affirm that students with ASD are heterogeneous and modifications to mainstream learning environments are required in order for them to participate in them (Jordan, 2008). Modifications include: reducing class size, individualising tasks and instructional methods, incorporating student interests into the curriculum and teaching social skills (Parsons et al., 2011; Roberts and Prior, 2006; Simpson et al., 2003). However, this requires mainstream educational structures to be adaptable to accommodate the unique needs of students with ASD. There are numerous reasons why adaptations may not take place in schools. For example, they may be at odds with prevailing school cultures, and the broader standards agenda that is currently influencing educational provision.

Schools could enable student agency and consequently their participation by offering students more choice in the school curriculum they follow. Most students in this study felt a choice of subjects would improve their enjoyment of, and participation in, school. It is considered best practice to include students with ASD in educational planning and evaluation (Reid, 2011; Simpson et al., 2003). This may increase student's perceived control over their learning and thus they may be more engaged and willing to participate.

The second theme discussed in this chapter was 'standing out' involving a perception of being different from peers and not fitting in. The experience of students with ASD in the current study closely mirror the extant literature on students' with ASDs experiences of social participation in mainstream education. In several prior studies students have reported that they perceived themselves to be different and that difference was in most cases a negative attribute (Carrington & Graham, 2001; Carrington et al., 2003; Humphrey & Lewis, 2008; Poon et al., 2012; Scuitto et al., 2012). In the study by Humphrey and Lewis (2008, p. 31) secondary school students with ASD expressed the sentiment "make me normal" and some held negative perceptions of their differences describing themselves as "retarded" or having a "bad brain". Several retrospective studies with adults with ASD have reported similar findings. Young adults with ASD in a study by Portaway and Johnson (2003, p. 437) expressed feelings of "not quite fitting" throughout their lives, including

during their schooling. Many participants were excluded educationally and others were excluded socially by their peers and this left them feeling like outsiders (Portaway & Johnson, 2003). Similarly, Autism Spectrum Australia (Aspect, 2012) conducted a survey of over 300 adults with Asperger's Disorder (AD) and High Functioning Autism (HFA). Over 70% of these respondents reported a pervasive sense of "not fitting in" during their time in education. In the current study students' responses to 'standing out' were explored. Some students attempted to conform by masking their differences through mimicking their peers, while other students spent time alone instead. The seeking of solitude could either reflect an active rejection of the playground norms or a lack of awareness or ability to conform to these norms.

Students were targeted and rejected by their peers and this was perceived to be due to their differences. All of the students reported that their peers were not aware of their ASD. Conceivably, one reason for rejecting difference might be a lack of awareness on the part of peers about the underlying reasons for the difference - namely the ASD. This explanation is supported by previous research by Humphrey and Symes (2011) in which they observed 38 adolescents with ASD over a two-day period and compared with those of school, age, and gender matched comparison groups of 35 adolescents with dyslexia and 38 with no identified special educational needs. Humphrey and Symes (2011) found that if a peer group had a lack of awareness and understanding of ASD this led to a reduced acceptance of difference and increased bullying and social rejection for students with ASD. They developed the 'reciprocal effects peer interaction model', which showed that social rejection of students with ASD led to increased isolation and loneliness (Humphrey & Symes, 2011, p. 400). This resulted in reduced motivation for social contact and more solitary behaviour and less opportunity to develop communication and social skills. Rejection therefore reinforced the seeking of solitude. This suggests a need to improve peer awareness and understanding of ASD.

The majority of the students in the current study had no or few friends and thus were not embedded in a social network of peers. These students reported not fitting in which indicates a poor sense of belonging. There is research to show that a poor sense of belonging at school is associated with decreased academic engagement and performance (Crosnoe, 2011; Osterman, 2000) school dropout (Bond et al., 2007; Furrer & Skinner, 2003), decreased odds of going to university (Crosnoe, 2011) as well as mental health issues such as anxiety and depression (Bond et al., 2007; McGraw, Moore, Fuller & Bates, 2008; Resnick et al., 1997). Research on children who have been formally excluded from school indicates that children experience other negative long-term impacts such higher likelihood of unemployment, low self-esteem and involvement with offending (Daniels & Cole, 2010; Macrae et al., 2003). Since the majority of the students in the current study reported feelings

of not fitting in, there may be a flow on effect on their academic achievement and future adult outcomes. However the nature of the methodology used in this study does not allow any causal links to be drawn.

The findings suggest a need for schools to intervene in ways that foster student's sense of belonging at two levels. Firstly, all schools need to modify their culture so that they are welcoming and celebrate diversity (Carrington, 1999). School culture appeared to be influence whether or not students experienced 'standing out'. For example, in Declan's case he experienced a sense of belonging when his current school displayed a welcoming attitude. There may also be a need to work with students at an individual level. Involvement in social skills programs may improve students' social understanding and ability to initiate social interaction with their peers and thus may enhance their sense of belonging. Many previous studies in the ASD field have acknowledged that social skills programs should be taught in mainstream schools to students with ASD and their typically developing peers (Carrington & Graham, 1999; Connor, 2000; Frederickson et al., 2010; Guldberg, 2010; Guldberg et al., 2011).

This chapter has developed an understanding of students' current experiences of participation in mainstream school. It enhances the findings of the previous chapters by providing insight into the day-to-day experiences of participation for students from their perspectives, including how students attempted to influence their participation in school. It has also illustrated some subtle differences in the perceptions of parents and students. For example, in relation to their perceptions of friendship, and it has highlighted the crucial importance of friendship from the students perspective. The next and final chapter of this thesis will discuss the results as a whole with reference to the extant literature, the implications for policy and practice and the directions for future research.

CHAPTER NINE: DISCUSSION AND IMPLICATIONS

This thesis has contributed to knowledge about the participation of students with ASD in mainstream school by incorporating the perspective of students with ASD and their parents and more so, by considering participation across schooling years as a whole. This study also addresses the general paucity of research about the participation of students with ASD in mainstream school. Additionally, this study has contributed to the field by way of application of the Life Course Theory (Elder & Giele, 2009) to understand participation in mainstream school in relation to the critical transitions and turning points and how agency is used in response to perceived challenges in the context of participation. Consistent with this theoretical approach, this thesis has uncovered some of the complexities of participation and the interplay of the individual and their environment.

This chapter is divided into five sections. The first section provides a summary of the findings before the findings of the study as a whole are reviewed in relation to the extant literature. Next, the implications for policy and practice are discussed. This is followed by an acknowledgement of the methodological issues, and finally, the implications for future research are outlined.

9.1 SUMMARY OF THE FINDINGS

The first results chapter explored how parents perceived and made sense of their children's participation in mainstream school over time. The findings indicated that parents perceived their children's participation was 'restricted'. They made sense of this experience as being the result of a combination of factors related to the school context, including lack of resources and an inflexible curriculum, and their children's characteristics, such as their social skills difficulties and rigidity in relation to non-preferred activities. They also discussed the 'variable impact of school staff' such as teachers and leadership personnel on their children's participation. They emphasised the need for school staff to understand ASD and its unique manifestation in each child, to take an interest in their individual child and to make accommodations to facilitate their participation. Finally, they perceived there had been two 'turning points', which were key events at which their children's participation had either increased or decreased. These were: the transition to secondary school and attending an ASD-specific placement.

The second results chapter described the participation trajectories of the students. The findings indicated that the majority of students with ASD experienced 'disrupted participation trajectories'

which involved frequent interruptions resulting in restricted participation at school for most of their schooling years. A minority (two students) experienced ‘relatively stable participation trajectories’, including stable attendance at mainstream schools and relatively few changes of school. However, they also experienced challenges in interacting socially with other students (consistent with ASD), which became more pronounced in high school. The educational trajectories of two students were presented to illustrate the two participation trajectory types. Both illustrated the complexity of participation for students with ASD by highlighting the multiple factors that influence participation.

The third results chapter revealed the ‘perpetual battle’ parents engaged in to support their children’s participation in mainstream schools. This involved ‘constant advocacy’ for accommodations to be made to the academic and social environment to facilitate their children’s education. However, in most cases, despite engaging in this perpetual battle, the result was poor educational participation for their children. There were barriers within school contexts, which substantially constrained the ability of most parents to significantly influence their children’s educational participation. For some the main barrier was a lack of communication from the school, while for others it was a perception that school staff expected passivity and this constrained their advocacy. Most parents perceived their children’s negative experiences of participation were the result of a failure of the education system and this led three parents to remove their children from the system altogether. Two home-schooled and the third organised a supported work placement for her son. They perceived this was a way to take control of their children’s education to ensure they received an appropriate education. The ‘perpetual battle’ altered parents’ lives. It affected their employment and the social, emotional and financial wellbeing of both parents and siblings.

The final results chapter presented the students’ current experiences of participation in mainstream school. The findings indicated that students were experiencing ‘academic mismatch’ and ‘standing out’ in mainstream schools. ‘Academic mismatch’ denoted the emergent tensions when school factors including the curriculum content, pedagogical and assessment practices were ill suited to the students’ individual characteristics such as their ASD-specific symptoms, and their academic abilities, learning styles and preferences. This mismatch impacted on their capacity to participate. Mismatch was experienced in two key areas: curriculum and curriculum-related tasks. ‘Standing out’ involved a perception of being different from their mainstream peers and not fitting in. Primarily ‘standing out’ was experienced during social interactions with peers in the playground; however there were some examples of ‘standing out’ during class time. Friendships acted as a potential buffer to ‘standing out’ for some students.

9.2 SYNTHESIS OF THE FINDINGS

The findings as a whole draw attention to four key areas for discussion, namely: the changeable nature of participation over time for students with ASD; how participation can be enabled when there is a match between student factors and the school environment; the dominance of the school environment in shaping the participation of students with ASD and their parents, and how the onus of responsibility for student participation rests with parents.

9.2.1 Changeable nature of participation in mainstream school

Disrupted trajectories characterised by restricted social and academic participation for most of their schooling was a prominent theme in the findings. Previous research on the participation of students with disability over the primary school years indicated that their participation became more restricted over time, with less hours of attendance in mainstream classrooms (Hanson et al., 2001; Wendelborg & Tossebro, 2010). In both of these studies it was concluded that the gap between the children's characteristics and the demands of their school environment increased over the course of primary school and the children were unable to keep up relative to their peers (Hanson et al., 2001; Wendelborg & Tossebro, 2010). Similarly, in this study students' social participation decreased over time, particularly once they entered high school. However, despite an overall pattern of restricted participation and decreased social participation, the findings also demonstrated that there was potential for change in participation for students with ASD in both trajectory types. Through application of the life course concepts of transitions and turning points, this study revealed several factors that could change student participation either positively or negatively. Firstly, changes in school staff such as front-line teachers and leadership personnel could either decrease or increase participation, regardless of the stage of schooling that this occurred. This confirms the findings of previous studies in the field, which indicate the crucial role of school staff in either supporting or impeding the inclusion of students with ASD in mainstream school (Humphrey & Lewis, 2008, McDonald, 2010).

This study also identified two key events in students' educational trajectories that led to significant changes in their participation: the transition to secondary school and attending an ASD-specific placement. Consistent with the findings of previous studies on transition to secondary school for students with ASD, in this study it was found to be a particularly difficult period of schooling for students with ASD (Dillon & Underwood, 2012; Dixon & Tanner, 2013; Maras & Aveling, 2006). This study adds to this literature by developing an understanding of how student participation was affected during this transition. It was found that for most students their participation decreased at

this time due to two factors. First, there was a gap between the expectations of independence in the secondary school environment and students' actual independence skills, and second, the peer environment became more complex and students were not equipped with the social skills to negotiate peer relationships.

This study also lends support to the conclusion of other researchers that successful transition is enabled when students with ASD and the secondary school are prepared for the transition (Dillon & Underwood, 2012; Dixon & Tanner, 2013; Maras & Aveling, 2006). However, this study indicated a need for ongoing transition support for students with ASD to be provided by their secondary school as two students who were initially provided with transition support leading up to secondary school experienced a decline in their participation later in year eight due to difficulties with peers.

Attending an ASD-specific placement led to an increase in student participation in that environment and facilitated their participation at mainstream school during that time period. However, for some students there were issues with integrating the AQ program with the mainstream curriculum, which at times impeded academic progress for students. Furthermore, the AQ placement was temporary and once students returned to mainstream school full time their social and academic participation declined and three of the eight students later exited mainstream school altogether. These findings differ to those of Keane, Aldridge, Coster and Clarke (2011) who conducted a long-term follow up study of the Aspect satellite class transition model in Australia by surveying 63 parents of children with ASD whose children had attended a satellite class for students with ASD within a mainstream school. Their results indicated that the majority of Aspect graduates remained placed in more inclusive educational settings. One possible explanation for the different findings could relate to the different contexts as AQ is a segregated school, whereas Aspect satellite classes are located within mainstream schools which may facilitate a smoother transition into mainstream classrooms.

Furthermore, students in the Aspect study made a gradual transition into mainstream classes and there was ongoing communication between the satellite teachers and the mainstream teachers for an extended period after the student left the satellite class (Keane et al., 2011). The parents in the current study did not, however, report such practices had taken place, which could suggest a more abrupt termination of the AQ placement. This provides further weight to the importance of transition support for students with ASD, in this case between ASD-specific and mainstream environments.

9.2.2 Participation can be enabled when there is a match between student factors and the school environment

It is evident from the findings of this study that participation can be enabled when there is a match between individual student factors and features of the school environment. This match occurred rarely for students in this study as the pedagogy, curriculum and classroom environment were not adequately adapted to individual students and therefore did not match their learning styles, interests and preferences or sensory needs. This resulted in restricted participation for most of their schooling. Since both school environments and students change over time ensuring an appropriate ‘match’ is an ongoing process. This corresponds to the Person-Environment-Occupation (PEO) model developed by Law et al. (1996). The PEO model acknowledges the dynamic interplay between the person, the environment, and the person’s daily activities (occupations). The fit between these three components may increase or decrease over time. It is proposed that when these three components overlap there is greater harmony in their interaction (Law et al., 1996). In contrast, where these components do not overlap, there is poor fit, generating restricted occupational performance and participation. As shown in this study, when there is a poor match between the student and school environment, in the context of an activity, this can lead to restricted participation at school.

According to Law et al. (1996), interventions to improve fit can be aimed at adapting the environment and/or improving the abilities of the person. Most of the parents in this study perceived that schools expected their children to adapt to the mainstream school environment, however they perceived their children were unable to adapt as inflexibility is a core diagnostic feature of ASD (APA, 2013). In these cases parents expected a one-way adaption – that school environments should be adapted to their individual children. Similar findings were also reported in a Canadian study by Penney (2013) of parents of children with ASD and co-occurring anxiety and/or depression. Parents reported a perception that the onus was on their children to adapt their behaviour to the school environment, even when they were unable to do so. These parents felt that the onus for change should instead be placed on the school staff to create a more accommodating environment (Penney, 2013).

If schools modify the classroom and playground environments this may enhance the willingness of students to engage in educational and social activities, as implied by participants in this study. Similarly in the book ‘Freaks, Geeks and Asperger Syndrome’, Luke Jackson (2002), a teenager

with Asperger's syndrome, indicated how he modified his own behaviour in response to the school's accommodations:

For some people school is like fitting a square peg in a round hole. For me at the moment the hole (school) has changed its shape slightly to accommodate me and the square peg (me) has tried to soften its edges. So a better description would be a rounded square trying to fit itself into a circle with sticky out bits. (p. 134)

However, there needs to be due consideration of the heterogeneity of students with ASD. Research on the developmental trajectories of children with ASD shows positive changes in social interaction skills over time. However, in this case, progress remained modest and was confined to the children on the higher functioning end of the spectrum (Baghdadli et al., 2011). Since not all students with ASD will be capable of adapting to rigid school environments, the onus of responsibility for making adaptions to increase their participation should be placed on schools.

9.2.3 Dominance of the school environment on the participation of students with ASD and their parents

Consistent with Life Course Theory, it was proposed that students with ASD and their parents had agentic capacity to influence their participation at school within the constraints and opportunities provided by school environments. Based on the findings, both parents and students demonstrated use of agency to influence student participation, but school environments were the dominant force shaping the participation of students with ASD and their parents in mainstream school over time.

Parents engaged in a range of advocacy, including monitoring schools, negotiating for adaptations and educating school staff about ASD. However the majority perceived that overall their advocacy efforts had had little influence on their children's participation in mainstream school. The empirical model of agency developed by Hitlin and Elder (2007) can be applied here to help understand parents' perception of restricted agency. In their model agency represents an individual capacity that is "both the result of individual differences (planfulness) as well as achieved successes (self-efficacy) and a sense of temporal, self-reflective understanding about one's life chances (optimism)" (Hitlin & Elder, 2007, p. 60). The majority of parents in this study reported a lack of previous success with their advocacy due to the inflexibility of mainstream schools. Their perceived self-efficacy is therefore likely to have been low. They also did not have a sense of optimism about their children's future, due to concerns that their children would not complete school and would continue to be dependent in adulthood. Consequently, they perceived their agentic capacity to

influence their children's participation in mainstream school was poor.

Some parents also perceived that they were expected to engage in particular ways during their interactions with the schools. For example, they perceived a pressure to be passive, agreeable and to treat school staff as the experts, in order to prevent exclusion from involvement in their child's education and decision-making. Interestingly, some of the parents chose to adopt a passive approach, possibly because they didn't want to alienate the teaching staff by making too many demands. They were unwilling to risk their child being excluded completely since they had no other options. However, when it became apparent that their children were not receiving an inclusive education in mainstream schools and that their advocacy attempts were having little influence over their children's education, several parents decided to remove their children from the mainstream education system (through home-schooling or a supported work placement). Parents perceived this decision enabled them to take back control of their children's education. Similarly, in a number of previous studies parents of children with disability have reported choosing to home school because of inadequate mainstream provision (Hurlbutt, 2011; Kidd & Kaczmarek, 2010; McConnell, 2006; McDonald, 2010; McDonald & Lopes, 2012; Parsons & Lewis, 2010; Reilly et al., 2002).

The findings from the student chapter revealed that the students displayed an awareness of their own learning styles and interests and wanted the curriculum to incorporate their interests. However, many of the students experienced academic mismatch as the curriculum did not fit their learning preferences, interests or abilities. Previous studies have described students' academic participation experiences, including stress due to the secondary school workload (Poon et al., 2012; Saggers et al., 2011), but have not documented the strategies used by students to negotiate their academic participation. The current study contributes to knowledge about how students with ASD negotiate their academic participation in mainstream schools. For example, some students reported that they managed 'curriculum mismatch' by refusing to participate. This indicates that students exercised some level of agency in mainstream schools in that they at times choose not to engage with everyday activities. However, overall their influence was limited as they were not included in curriculum development and therefore students could not change the curriculum to enhance their participation in it. Hoogsten and Woodgate (2010, p. 335) suggest that a prerequisite for the participation of children with disabilities is "choice or control over what they are taking part in". This highlights the need for schools to consult students with ASD and include them in their own educational planning and decision-making.

Some students in this study felt pressured to conform to their peer group and did not want to be perceived as different. This finding supports that of previous studies incorporating the perspectives of students with ASD where students have reported masquerading at school (Carrington et al., 2003; Humphrey & Lewis, 2008). This study adds to this literature by contributing a deeper understanding of the range of strategies used by students with ASD to manage their social participation at school including: (a) masking their differences through mimicking their peers, (b) avoiding interactions with them in the playground and (c) retaliating against bullies. Detrimental consequences of some of these strategies were evident. For example, retaliating against bullies led to students being disciplined by their schools. Overall, the findings suggested that although the students actively attempted to influence their social participation, their capacity to do so was constrained by systemic factors such as a general lack of awareness of ASD amongst their typically developing peers and lack of acceptance of difference leading to bullying. This underscores the need to improve peer awareness so that typically developing peers are more understanding of the impact of ASD on individual students' behaviour and become more accepting of diversity and individual differences. The findings also suggest a need for classroom-based social skills training for the students with ASD to improve their social understanding of appropriate social mores within the school context. Examples of social skills programs will be discussed in the implications section.

In the current study a number of factors were identified that facilitated student participation. These included: (a) a welcoming school culture that celebrated diversity, (b) the willingness of schools to make adjustments, (c) preparation for transitions, (d) effective home-school communication and collaboration, (e) key personnel with an investment in the inclusion of the child such as a principal or case manager and (f) staff having an understanding of ASD. What is striking about this list is the fact that all of these factors are related to the school environment and not to student characteristics. The factors identified in this study are noticeably similar to the conclusions of McDonald (2010) who reported that the children with ASD in her study found "educational fit" in mainstream environments where there was: (a) a welcoming school culture; (b) a supportive Education Support Unit; (c) equal and trusting partnerships between parents and staff; (d) staff who were devoted and committed to the development of the child and who were self-aware about their expertise; (e) student-centred decision making, and (f) a key member on staff to promote evidence-based inclusive practice (McDonald, 2010, p. 181). Furthermore, in a study in the United Kingdom by Waddington and Reed (2006) of parent perceptions of the factors that facilitate or impede the inclusion of their children with ASD in mainstream schools, parents identified school factors as the

most influential. For example, the school's commitment and willingness to accommodate students with ASD, and the effectiveness of their home-school communication strategies were the most pertinent factors in moderating the success of inclusion. Additional important factors were funding and teacher training. Funding was perceived to be the biggest impediment to inclusion (Waddington & Reed, 2006).

The school environment has also been found to be the most important factor impacting the school participation of students with disabilities. For example, Coster et al. (2013) compared school participation patterns of students ages 5–17 with and without disabilities in Canada and the United States and investigated whether features of the school environment were perceived to facilitate or impede their participation. They found that parents of students with disabilities were significantly more likely to report that aspects of the physical and social environment impeded their children's school participation and that there were inadequate resources to enable their participation (Coster et al., 2013). Taken together, these findings reinforce the importance of modifying school environments to facilitate the participation of students with ASD and students with other disabilities.

9.2.4 The onus of responsibility for student participation was on parents

The findings of this study as a whole indicate that the onus of responsibility for facilitating student participation is on parents. This is despite the conclusions stated above that the school environment was the dominant force shaping participation and that most parents perceived that their influence on participation was limited. Several examples from the findings demonstrate how the onus of responsibility for student participation was shifted onto parents, both in relation to accessing a mainstream school for their child and facilitating their subsequent participation in school.

Half of the parents in this study reported that they had been discouraged by principals from enrolling their children in some mainstream schools over the course of their children's schooling. This occurred across all sectors of the education system, including independent, Catholic and government schools. They reported that these principals claimed that the school could not support their child, as they did not have adequate resources. This led to parents having to engage in a process of searching for a mainstream school that would accept their child. These findings in relation to enrolment practices are consistent with two previous Australian studies of the experiences of parents of children with ASD in relation to mainstream schools where parents have reported experiencing informal exclusion when attempting to enrol their children in mainstream school (Lilley, 2012; McDonald, 2010). Similar to the parents in this study, in both Lilley's (2012)

and McDonald's (2010) studies, parents were reportedly advised that the school had inadequate resources and that their child would be best suited to another school, and were often redirected to another school sector. These schools appeared to shift responsibility for the students with ASD onto other schools. Parents in both the studies also reported having to search for a mainstream school that would accept their child (Lilley, 2012; McDonald, 2010). In Lilley's (2012) study some parents reported having to acquiesce and accept a more restrictive placement in a support class or special school, even though this was not their first choice of provision. However, a difference noted between the current study and Lilley's work is that Lilley's findings were in relation to negotiating initial school entry into primary school, whereas this study developed an understanding of participation across children's schooling. The findings of this study indicate that parents continue to experience difficulty enrolling their children in mainstream school throughout their schooling.

Many of the parents in this study also perceived that accommodations to support the learning and participation of their children in the curriculum were not readily made by mainstream schools even though they are legally required. Instead parents had to engage in 'constant advocacy' in an attempt to ensure they were implemented. This parallels the findings of a Canadian study by Penney (2013, p. 85) on the perceptions of nine parents of young people with ASD and co-occurring depression and/or anxiety disorders, which found that parents were placed in a position of "constant vigilance" to ensure appropriate accommodations at school. However, in the current study many parents perceived that despite their 'constant advocacy' adequate accommodations had not been made across their children's schooling. This finding appears contrary to the policies and procedures set out by the educational authority, which indicate that the department's financial support is contingent on the schools having made adjustments (Education Queensland, 2013). It also suggests failure on the part of mainstream schools to meet their legal obligations under the *Disability Standards for Education* (2005) to make adjustments to enable the participation of students with ASD in education. This conclusion is supported by a recent review of the Disability Standards for Education (2012) in Australia, which reported that many schools failed to comply with the Standards and there are few consequences for education providers that breach the standards or fail to act on complaints (Department of Education, Employment and Workplace Relations [DEEWR], 2012).

Recommendations to improve the accountability of mainstream schools will be made in the implications section.

Some parents in the current study also provided examples of their children being placed on a restricted timetable at school (with short days and thus limited opportunities to participate in the entire school curriculum) and many reported that they had been frequently been contacted by

schools to collect their children prior to finishing time following behavioural incidents. Similar findings were reported in a previous study by Reid (2011), which surveyed 739 parents of children with ASD in the United Kingdom about their children's education. One in three of these parents reported having to pick their child up early from school when the child was not sick, and one in five had been asked to do this more than four times (Reid, 2011). In the current study exclusion also extended to extra-curricular activities such as school camps, where two parents were expected to stay close by in case their child was asked to leave the camp early. In both cases they were then asked to collect their child prior to the end of the camp.

The findings indicate that parents of children with ASD are being co-opted to fill gaps in the mainstream education system. For example, when there are limited resources to support the participation of their child with ASD in a particular activity parents are called upon to remove their child leading to restricted participation at school. It may be that resources were limited in these schools, as parents reported a perception that lack of funds impeded the ability of mainstream schools to make appropriate modifications. Similarly, in a study by Waddington and Reed (2006) in the United Kingdom parents reported the perception that insufficient funding was the most significant factor affecting the successful inclusion of their children with ASD. However, the situation may be more complex, as lack of funds can be used as the rationale for not making modifications, thereby masking an underlying unwillingness by schools to take responsibility for students with ASD.

The burden of responsibility for facilitating their child's school participation had a significant impact on these parents' lives. Some parents reported that the frequent restrictions on their children's attendance and participation at school caused them to reduce their employment and or to give up work entirely. This led to decreased household income and to housing instability for two families. These findings are supported by previous studies where parents of children with ASD have reported reducing or giving up employment due to the level of involvement required in their children's education (Batten et al., 2006; McDonald, 2010; Penney, 2013; Reid, 2011). This is also echoed in the broader literature on the lived experiences of parents of children with ASD where parents have reported having to reduce or give up work entirely to become primary caregivers of children with ASD (Bourke-Taylor, 2012; Ryan & Runswick Cole, 2009; Seltzer et al., 2001; Stoner & Stoner, 2014). Taken together, these findings indicate that parents of children with ASD are involved to a considerable degree in the lives of their children with ASD and this requires them to alter their own lives. This supports the proposition of Life Course Theory that lives are lived interdependently (Elder & Giele, 2009).

The findings of this study indicate a high degree of interdependence between children with ASD and their parents with parents' lives being significantly affected by their children's restricted participation at school. This highlights the need for educators to recognise the implications for families if they fail to take responsibility for enabling the participation of students with ASD. It also suggests a need for schools to provide greater support to families.

9.3 IMPLICATIONS FOR POLICY AND PRACTICE

There are a number of implications for mainstream education policy and practice arising from the findings of the study documented in this thesis. Each of these will now be discussed.

9.3.1 Engaging parents and students with ASD in educational planning

Research shows that engaging parents in educational planning is critical to improving student achievement (Harris & Goodall, 2007). The parents in this study desired regular communication with schools and wanted to work together with them in partnership to support their children's participation. In Australia, Positive Partnerships provides free workshops and information sessions for parents/carers of school age children with ASD with aim of equipping parents with the skills to form mutually beneficial partnerships with their child's school (Partnerships between Education and the Autism Community [PEAC], 2014). Parents of children with ASD may benefit from accessing such training.

A further tool that could be used by schools is 'structured conversations'. These were developed as a method for engaging parents in educational planning as part of the 'Achievement for All Project' in the United Kingdom which is a whole-school approach to school improvement (Department for Children, Schools and Families [DCSF], 2009). The purposes of the structured conversation are to:

Establish an effective relationship between parent and the key teacher; allow the parent an opportunity to share their concerns and, together, agree their aspirations for their child; set clear goals and targets for learning and improvement in wider outcomes; determine activities which will contribute to the achievement of those targets; identify the responsibilities of the parent, the pupil and the school; agree the date and time of the next meeting; clarify the most effective means of communication between meetings. (DCSF, 2009, p. 4)

This approach could be applicable in schools in other jurisdictions at parent-teacher meetings, including educational planning meetings. It aligns with best practice in ASD education and

inclusive education, as it acknowledges that education is best supported by collaborative relationships with parents and consultative decision-making (Lynch & Irvine, 2009).

Students with ASD should also be supported to be involved in their own education. The findings of this study highlight that students are aware of their learning needs and preferences and can articulate these to school staff, if given the opportunity and the right supports to enable them to do so. In the United Kingdom an example of good practice in this area is the National Autistic Society's Broomhayes School, which is an ASD-specific school. Each term all students have an individual planning meeting at which they have an opportunity to share what they enjoy about school, discuss the type of support they need, and set their own educational targets to work towards (Reid, 2011). This type of practice could be implemented in mainstream schools, if students with ASD were routinely included in IEP meetings. Students with ASD would need to be supported to participate in IEP processes through the use of visual aids to help them reflect upon and document their goals.

Student involvement in decision-making about their day-to-day education should also be supported. An example of good practice in this area is the ASD NEST program used in select New York schools. This program involves 'nest classrooms' within mainstream primary schools, which are comprised of students with ASD and typical peers (Koenig, Bleiweiss, Brennan, Cohen & Siegel, 2009). One of their strategies is to give students with ASD opportunities to make choices in the classroom throughout the school day. These choices are not necessarily big, for example: "which colour marker do you want to use?" (Koenig et al., 2009, p. 9). Providing small choices throughout the day gives students with ASD a sense of control and this has been found to increase their engagement in classroom activities and decrease their non-compliance (Koenig et al., 2009). This is a simple strategy that could be implemented by classroom teachers in other jurisdictions.

9.3.2 Advocacy support for parents

The findings of this study highlight the need for advocacy support for parents of children with ASD when negotiating with mainstream schools. Although all of the parents in this study engaged in 'constant advocacy' many perceived that their efforts had done little to improve their children's participation in mainstream schools over time. External advocates may have assisted them in their dealings with education professionals. Advocacy supports already exist for parents of children with ASD. For example, in the United Kingdom the National Autistic Society (NAS) provides an autism helpline and as part of this service they provide advice to parents on legal issues and can act as advocates for parents on range of issues including education (NAS, 2014).

Parents may also wish to become involved in systems advocacy. Previous qualitative research with 36 mothers of children with ASD in the United Kingdom on their involvement in advocacy indicates mothers may feel a sense of empowerment and satisfaction through engaging in systems advocacy (Ryan & Runswick Cole, 2009). There are a number of Australian organisations in which parents could become involved, that lobby the federal government in relation to improving access and participation in education for children with ASD and other disabilities. These include Autism Aspergers Advocacy Australia (A4, <http://a4.org.au/a4/>) and Children with Disability (CDA, <http://www.cda.org.au>). In Queensland parents can become members of Queensland Parents for People with a Disability (QPPD, <http://www.qppd.org>). This organisation supports individual families to assert the rights of their family member with a disability to be included in education, work, housing and community life. They also engage in systems advocacy to lobby for change in education, employment, and housing for all people with a disability in Queensland (QPPD, 2014).

9.3.3 Increased awareness of ASD in mainstream schools

This study reinforces the need to increase peer understanding of ASD. The students with ASD in this study universally experienced bullying. Some students and parents suggested that bullying could be reduced, if peers had greater awareness of ASD and its influence on students' functioning. The need for increased peer understanding to enable the inclusion of students with ASD has previously been acknowledged in the literature (Humphrey, 2008; Symes & Humphrey, 2010). This might involve a school-based education program for all students. A short film explaining ASD was produced by Autism Awareness in Australia and was screened in Australian primary schools (Autism Awareness, 2011) and could be screened in schools in other jurisdictions. A more in-depth ASD education program should also be implemented in mainstream schools. Wendy Symes, a researcher based in the United Kingdom has recently developed an intervention to improve the social inclusion of students with ASD in mainstream schools. The intervention includes eight 20-minute sessions to teach peers about ASD, the difficulties students with ASD may face, how students with ASD can be supported and also celebrates the positives of ASD. It also includes eight 30-minute small group sessions where the students with ASD can develop social skills (W. Symes, personal communication, October 13, 2013). Symes is currently evaluating the efficacy of this intervention through a randomised control trial (RCT) in four schools. If it is proven to be efficacious, it could be implemented in schools in other jurisdictions.

There is also a need to increase teacher understanding of ASD. In this study parents reported that teachers who were knowledgeable about ASD were generally compassionate and willing to make

accommodations to enable student participation. However, parents perceived that these teachers were exceptions. Research from the perspectives of mainstream teachers on their attitudes towards the inclusion of students with ASD indicates that mainstream teachers generally have positive attitudes (Humphrey & Symes, 2011; McGregor & Campbell, 2001; McGillicuddy & O'Donnell, 2014; Park, Chitiyo & Choi, 2012) and are willing to develop their knowledge and expertise in ASD, if professional development is provided (Humphrey & Symes, 2011).

Specific professional development in ASD is currently being delivered to Australian teachers via Positive Partnerships. This is a national program of professional development designed to increase understanding, skills and expertise of teachers and other education personnel in working with students with ASD. It is conducted over five days. Participants also have access to an online learning portal with learning sessions on a range of topics including: supporting behaviour; communication; bullying; transitions and making friends (PEAC, 2013). Research examining the impact of the professional development program indicated positive improvements in teachers' classroom practices, including making curriculum adjustments following participation in the program (Kishida, 2011). However, in 2010 the program had only reached 1% of Australian teachers to date (Allen Consulting Group, 2010). It is likely that this figure has increased since 2010. As the program has been extended until 2015, it is hoped that the program will further extend its reach. However, issues inherent in the uptake of this type of program should be acknowledged. For example, teachers need the support of their school principal to cover the cost of teacher relief time so that they can attend the five-day program during school time. The program is voluntary and therefore relies on teachers' interest and motivation to participate. It could be necessary to modify the program so that it is compulsory for teachers if they have a student with ASD in their class. There is also a need for ASD training to be provided to pre-service teachers as part of their university curriculum, so that new graduates have a better understanding of student diversity.

9.3.4 Social skills training in mainstream schools

It is recommended that social skills training be provided to children with ASD and their peers in mainstream schools. All parents in this study indicated their children had difficulty with social interaction. Many felt this was the main impediment to their children's participation at school, with all students experiencing social exclusion at some point in their schooling. Consequently, these parents wanted schools to provide social skills training at school. In a number of previous studies, parents of children with ASD have also identified this as a pressing need in mainstream schools

(Batten et al., 2006; Brown et al., 2012; Reid & Batten, 2006; Rowley et al., 2012; Spann et al., 2003). The Program for the Education and Enrichment of Relational Skills (PEERS®) (Laugeson & Frankel, 2010) could be implemented in schools. This is a 14-week evidence based social skills training intervention for adolescents and young adults with ASD. Another social skills program which could be adopted in schools is the Secret Agent Society (SAS) which comprises of a computer game, board game and social skills books which teach children with ASD about emotions, friendships, bullying and coping (The Social Skills Training Institute, 2014). The Circle of Friends approach (Newton & Wilson, 1996), which involves mobilising the young person's peers to provide support and engage in problem solving with the student with ASD, could also be implemented in schools. To date there has been limited research on the implementation of these programs within mainstream environments and this continues to be an area much in need of future research attention.

9.3.5 A continuum of educational provision

The results of this study suggest that at present mainstream schools may not be the most appropriate placement for all students with ASD through all of their schooling. Students with ASD are heterogeneous in terms of their learning profiles and strengths and as Jordan (2007) notes:

The degree to which individuals can and should be taught alongside typical peers depends on the severity of their unique need, the expertise and attitude of the teaching staff (and their access to additional support) in mainstream settings and the adaptability and flexibility of the mainstream situation. (p. 117)

Furthermore, a recent international review of the evidence on best practice in educational provision for children on the autism spectrum reported: "there is no evidence to suggest that a single intervention will meet the needs of all learners or that any single intervention or technique stood out from the others as superior for a majority of children" (Guldberg et al., 2011, p. 66). Therefore it is recommended that a continuum of educational options be provided so that every student has access to an educational environment that meets their unique needs (Batten et al., 2006; McDonald, 2010; Reid, 2011). This includes access to ASD-specific schools, specialist classes within mainstream schools and fulltime mainstream school placement. This position is supported by the Australian Advisory Board on Autism Spectrum Disorders (2010) and by a number of other Australian and international researchers in the field (Batten et al., 2006; Eaves & Ho, 1997; Guldberg et al., 2011; McDonald, 2010; Reid, 2011; Stewart, 2012; Williams White et al., 2007). Ideally, educational placements across this continuum should be fluid and be continuously reviewed, as child characteristics, such as their abilities and skills, and program characteristics, such as the knowledge

of staff and availability of supports, are both likely to change over time (Jordan, 2007; Williams White et al., 2007). Placement decisions at any point in a child's educational trajectory should be made based on the best match between child and program characteristics at that time.

9.3.6 Continuing the development of inclusive education

Providing access to a range of educational provision does not negate the need to continue to develop inclusive mainstream schools. Many students with ASD may be best catered for in mainstream schools, if these environments can become more responsive to student diversity. There is a growing body of literature which identifies the elements of effective educational programs for students with ASD and outlines guidelines for including students with ASD in mainstream schools (Bullard, 2004; Connor, 2000; Crosland & Dunlap, 2012; Dawson & Osterling, 1997; Guldberg, 2010; Harrower & Dunlap, 2001; Humphrey, 2008; Iovannone et al., 2003; Lynch & Irvine, 2009; Simpson et al., 2003). The paper by Lynch and Irvine (2009) offers particular promise as it identifies the commonalities between the elements of best practice in education of students with ASD and an “authentic inclusion” model. The means by which these elements can be integrated to create a “unified model of education” to improve the education of all students are described (Lynch & Irvine, 2009, p. 845).

However, recent literature highlights a gap between research on educational interventions and their implementation in mainstream schools (Parsons et al., 2013). To address this issue, Parsons et al. (2013, p. 269) argue “building collaborative partnerships between researchers and school practitioners is central to achieving improved understanding of, and outcomes for, pupils on the autism spectrum”. They present a model of collaboration between researchers and practitioners from autism schools: the Pan-London Autism Schools Network research partnership (PLASN-R)(Parsons et al., 2013). PLASN-R comprised 10 schools and eight researchers. To date the partnership has led to the completion of two research projects: a survey on mental health/emotional and behavioural difficulties, and study on the links between education and adult outcomes for people with ASD (see Wittemeyer et al., 2011). The authors acknowledged a number of challenges encountered by PLASN-R in relation to resourcing the collaboration, the time commitments required of both school staff and researchers and the need to support a mutual process of “knowledge exchange” between schools and researchers rather than a unidirectional transfer of research knowledge to schools (Parsons et al., 2013, p. 276). Despite such challenges, such an approach offers promise and could serve as a model to develop collaborative partnerships between mainstream schools and researchers in other jurisdictions with the aim of improving the inclusion of

students with ASD. In Australia, the Cooperative Research Centre for Living with Autism Spectrum Disorders has recently commenced a program of research focusing on maximising the opportunities for students with ASD to participate at school, with much of the research being embedded within mainstream classrooms (Autism CRC, 2014).

9.3.7 Improved accountability in Australian schools

There is a need for a stronger accountability framework in Australian schools in relation to students with disability. In this study parents perceived that mainstream schools had rarely made sufficient accommodations to support the learning needs of their children with ASD. Although schools are legally obligated to make such accommodations under the *Disability Standards for Education (2005)*, a recent review of the Standards reported that there was a lack of awareness about the Standards across the education sector (DEEWR, 2012). The review found that the Standards were not met in practice as students with disabilities could not enrol and participate in education ‘on the same basis’ as typically developing students (DEEWR, 2012). The review also reported that although many schools failed to comply with the Standards, there were few consequences for these schools (DEEWR, 2012).

To improve accountability it was recommended in the report that the Australian Attorney-General, revises the Standards “to establish clear requirements for compliance with each part of the Standards [and] investigate options for compliance reporting against the Standards for education providers” (DEEWR, 2012, p. ix). Options might include an annual system of reporting by education providers and penalties for non-compliance (DEEWR, 2012). Current national measures of schools focus on academic standards for example school National Assessment Program – Literacy and Numeracy (NAPLAN) results. The Commonwealth Government could develop key performance indicators for school inclusion based on the Index for Inclusion developed by Booth and Ainscow (2002) and include a measure of parent satisfaction with inclusive practices and publish these results on the ‘My School’ website which shares information about the performance of schools with the Australian public (ACARA, 2014). These changes would focus school leadership teams on looking at more than just academics in league tables. This could encourage a focus on the provision of inclusive education.

There is also a need to reform the structure of the complaints process for parents pursuing discrimination complaints under the *Disability Standards for Education (2005)*. Although the parents in the current study did not report engaging in such processes, the recent review of the Standards indicated that the complaints process is currently inaccessible for parents of children with

disabilities for a number of reasons. It places the onus on parents to pursue their individual case, which can be time-consuming and costly. The process can also be complex to navigate. Furthermore, parents may be reluctant to make complaints to the relevant anti-discrimination authority for fear of potential adverse consequences for their child at school (DEEWR, 2012). Consequently, the review recommended that the Australian Attorney-General's Department consider the issues identified regarding the current complaints process and develop alternative dispute resolution options such as mediation and arbitration (DEEWR, 2012). It was also suggested that the Australian Human Rights Commission be given greater authority to take action in response to breaches of the Standards without a parent having to take action first (DEEWR, 2012).

9.3.8 Changes to school disciplinary responses in Australian schools

School disciplinary responses require reconsideration. The majority of the students in this study faced repeated suspensions and some had been excluded. In some cases these behaviour management strategies reinforced students' maladaptive behaviours. For example parents reported that their children were aware that if they acted out they would be suspended and would not have to attend school. Consequently they did so repeatedly over the course of their schooling. Parents indicated that behavioural incidents were often directly related to their children's ASD and frequently led to suspensions. The onus is on schools to take students' disability into consideration when determining a course of disciplinary action. In the United States this has been legislated federally as part of the *Individuals with Disabilities Education Act (IDEA) 2004*. Under this Act schools must consider the impact of disability when determining disciplinary actions for students with disabilities. A student may not be suspended or expelled if an assessment is made that the behaviour of concern was related to his or her disability, and the school did not have appropriate accommodations in place. In which case schools are then required to complete a functional behavioural assessment and develop a behavioural intervention plan (U.S. Department of Education, 2014). The *Australian Disability Standards for Education 2005* do not currently have a section that details procedures that schools must follow when disciplining students with disabilities. Inclusion of a section similar to that in the IDEA (2004) would ensure Australian schools have a legal obligation to consider the impact of disability when implementing disciplinary actions.

9.3.9 Changes to the model of special education support in Queensland mainstream schools

The results of this study also suggest that the model of special education support in Queensland mainstream schools also needs reform. The students in this study were unable to access support prior to a definitive diagnosis. As many students in this study were not diagnosed until late primary

school, they had spent most of primary school without special needs support. This suggests the need for support to be available for students prior to diagnosis based on their additional needs. Currently access to the Educational Adjustment Program in Queensland is contingent on a medical diagnosis and verification by Education Queensland (Education Queensland, 2013). However, Education Queensland needs to provide educational adjustments for any students who have special needs regardless of formal diagnosis if their inclusion is to be fully realised.

More flexible models of special education support need to be implemented. Parents in this study perceived that there was a support mismatch and that their children required more one-on-one support, despite students not wishing to appear different. One improvement could be an increased emphasis on small group work within the mainstream classroom with a specialist teacher/teacher's aide or in a satellite class within mainstream school that contains both students with ASD and mainstream peers (see ASD Nest Program, Koenig et al., 2009). This could be supplemented with individualised curriculum modifications to support student learning and participation.

In this study, parents provided few examples of educational adjustments being made to support the learning needs of their children with ASD, though students expressed a desire to study a curriculum based on their interests and learning styles. Processes like IEPs and EAPs already exist in Queensland schools however the parents in this study indicated that they are not being implemented appropriately. They reported that IEPs remained unchanged for long periods of time and that the goals in the IEPs were not necessarily relevant to their child. Furthermore, parents were not always included in these planning processes and the parents reported that the students were not included, which is contrary to Education Queensland's policy on IEPs (Education Queensland, 2014). Best practice in IEPs involves 12 monthly IEP goal setting with reviews every six months and inclusion of parents and students in goal planning. Furthermore Education Queensland (2014) states that EAP profiles should be completed with the student (where appropriate). Schools are required to formally review EAPs every three years, but are encouraged to engage in more regular reviews as part of regular school planning processes (Education Queensland, 2013). Reforms to schools practices are needed to ensure they comply with best practice in IEP and EAP planning to guarantee appropriate curriculum modifications are being made for students with ASD.

The findings of the current study support the need to increase funding for special needs support in Queensland schools. Parents in this study universally commented on the insufficiency of funds to support their child's educational needs. The Commonwealth Government has recently recognised the need to provide further funding to the States and Territories and has implemented the More

Support for Students with Disabilities (MSSWD) National Partnership. Under this initiative The Department of Education, Training and Employment (DETE) in Queensland is currently receiving \$32.9 million in Commonwealth funding over three years. The initiative aims to promote school-wide inclusive practices and increase understanding of the *Disability Standards for Education 2005* and support school leaders, teachers, teacher aides and support staff to improve the learning experiences and educational outcomes of students with disabilities (DETE, 2013).

Resources could also be allocated differently. Parents in this study reported concerns that schools were not transparent about how they used special needs funding. The Department of Education, Training and Employment (DETE) could consider changing to individualised special education budgets and giving parents control over their own child's budget. This may enable a more flexible approach to support each child's unique needs. This is being implemented in the United Kingdom under the Children and Families Bill (Department for Education, 2013). There are potential pros and cons to this model - parents may feel an increased sense of choice and control over how money is spent on their child's education. However, they may also feel additional pressure associated with taking further responsibility for coordinating their children's education (Reid, 2011).

9.4 METHODOLOGICAL ISSUES

A strength of this study was the use of Life Course Theory (Elder & Giele, 2009) to understand the whole of school participation of students with ASD in mainstream schools. The concept of turning points proved particularly useful for exploring changes in participation over time and for identifying key events that led to increases or decreases in student participation. This study has also contributed empirical knowledge about how life course concepts such as agency and linked lives manifest in the lives of students with ASD and their parents. This theory has the potential to inform future studies in this area.

A further strength of this study was its methodological contribution. Innovative interview strategies such as a Social Story™, PCST™, drawings and visual interview schedule were used to maximise the participation and contributions of the students with ASD (Harrington et al., 2013). The rich data collected from the students in this study demonstrate the importance and value of including their perspectives in future qualitative research and the importance of the researcher's role in supporting student participation. Participation trajectory grids, which were a method adapted in this study from life course grids (Parry et al., 1999) also proved to be useful data collection tool for documenting

student participation over time. They could be employed in future research examining the educational participation over time of a broad range of populations.

The recruitment method and sample could be considered limitations of this study. The majority of participants were recruited through an ASD-specific organisation, AQ. As a consequence of using AQ for recruitment, parents may have been accessing an AQ placement for their child because they were not successfully participating in mainstream education. Thus the sample may have been biased towards students who had had a negative experience in mainstream schools, and instead chose an ASD-specific alternative. Furthermore, the staff of the organisation identified potential participants and sent participant information sheets to them. Thus, they had the authority to decide who should and should not receive information about the study based on their own assumptions about the competence of potential participants. This had implications for the study sample in terms of selecting the voices that were heard. Those young people with ASD who were perceived to be too impaired or vulnerable, may not have been given the opportunity to participate. This means the sample may represent the voices of more ‘able’ students and their particular experience in mainstream school.

The sample size was small (eleven parents and eight students), and was neither ethnically nor geographically diverse. The participants were recruited via purposeful selection to meet specific inclusion criteria. The sample was comprised of Caucasian families in an urban area in Queensland. The majority of the parent participants were mothers and the majority of student participants were male. The limited representation of fathers’ perspectives is consistent with a recent review, which reported an underrepresentation of fathers in empirical investigations of children with ASD (Braunstein, Peniston, Perelman & Cassano, 2013). The results of this study are therefore context-specific and may not be generalisable to the wider population of students with ASD. They do however provide an in-depth understanding of these particular parents and students’ experiences of participation in mainstream schools. The results are consistent with the findings of other studies in this area in Australia (Hay & Winn, 2005; McDonald, 2010; Saggers et al., 2011) and the United Kingdom (Batten et al., 2006; Reid, 2011; Humphrey & Lewis, 2008). This suggests that the findings are not isolated experiences of a distinct set of parents and students with ASD.

Further potential limitations relate to the research design, which relied on the self-report of participants through interviews. The data obtained via these interviews have not been triangulated through another method such as direct observation of students at school. As such the candidate cannot comment on what is actually going on in mainstream schools. Rather the perspective of

students and parents about their experiences of participation is presented. This research was underpinned by an interpretivist epistemology, which focuses on perceptions and experiences, not objective truth. It has successfully captured the perceptions of students and parents on their participation in mainstream school. The research does not obtain the perspectives of all the key players in schools, for example principals, teachers and other school staff. Other prior studies have successfully captured these perspectives via case study approaches (Hay & Winn, 2005; Humphrey & Lewis, 2008). This study adds to the extant literature, by providing understanding of the participation trajectories of students with ASD from a life course perspective.

Since the candidate aimed to use strategies to maximise the participation of the students in the research process, the fact that the student interview guide was not piloted with young people with ASD could also be considered a limitation. In retrospect, it may have been useful to set up a reference group of young people with ASD. This could have been used to obtain their feedback on the information to be gathered, the best methods for gathering it and could have assisted with further refining the interview schedule (Morris, 2003). Including young people in the research design phase would have been more inclusive. Furthermore, it would have been beneficial to conduct repeat interviews with each student. In their interviews each student was able to discuss what they did and did not get to do at school, what they liked and did not like about school, and whether they felt they fitted in at school and why. This provided rich and valuable insights into their own experiences. Repeat interviews may have allowed them the space in which to feel more comfortable to express their views and would have allowed exploration of their experiences of participation in greater depth (Harrington et al., 2013).

9.5 FUTURE RESEARCH

This study has enhanced understanding of the experiences of participation for students with ASD in mainstream schools in Queensland. Previous Australian research has also been limited to small-scale qualitative research in individual states. These studies have revealed that there are a number of barriers to the participation of students with ASD in mainstream schools (Hay & Winn, 2005; Saggers et al., 2011). Nation-wide research on a larger scale is needed to understand the extent to which students with ASD attending mainstream schools in other parts of Australia have similar experiences. Several national studies have shown this to be the case in the United Kingdom (Barnard et al., 2000; Batten et al., 2006; Reid, 2011). It is hoped that the recently established Cooperative Research Centre for Living with Autism Spectrum Disorders, (Autism CRC), an Australian national research program that includes a program on enhancing teaching and learning,

will address this gap. The Autism CRC is aiming to provide a comprehensive understanding of the issues facing students with ASD in Australian mainstream schools and will make recommendations to the Australian Government about ways to improve their participation (Autism CRC, 2013).

This study investigated the perspectives of students and parents about their experience of participation in mainstream school. Future research is needed to obtain a diversity of perspectives. Research with multiple stakeholders including principals, teachers and peers would aid understanding regarding their perspectives on the participation of students with ASD and their perceived influences on student participation. A multiple case study design could be adopted to explore stakeholders' perspectives across different school contexts (e.g., state, catholic and independent schools).

As stated earlier, the sample was limited to Caucasian families living in an urban area in Queensland. Research in the United Kingdom has indicated that students of Afro-Caribbean origin are disproportionately excluded from mainstream schools (Macrae et al., 2003). Students with disabilities who are also from minority backgrounds may experience multiple disadvantages in education. It would be useful to explore the perspectives and experiences of school participation of students with ASD from Indigenous and Culturally and Linguistically Diverse (CALD) backgrounds living in rural and urban areas. These insights may provide additional recommendations regarding the specific needs of these students.

Fathers' perspectives are underrepresented in empirical investigations of children with ASD (Braunstein et al., 2013). Future research could explore fathers' experiences and their perspectives on their role in supporting the education of children with ASD, thus aiding in understanding any perspectives and experiences that may be particular to fathers.

There is also need to focus on the experiences of female students with ASD in future research as they are underrepresented in the research to date (including the current study). The literature suggests that females with ASD are able to mask their differences and social difficulties (Lai et al., 2011) and are frequently diagnosed later (Giarelli et al., 2010). Hence their educational and social needs may be less well understood.

Prospective, longitudinal research is needed to learn more about the educational participation experiences of students with ASD over time. A longitudinal design could be used to track a cohort of students and analyse changes in their participation and educational outcomes over time. A

quantitative approach would aid in understanding the relationships between factors and their relative influence on participation across student trajectories.

9.6 CONCLUSION

This thesis has contributed to our understanding of the participation of students with ASD and their parents in mainstream by incorporating both parent perspectives on the whole of schooling experience and student experiences. Given the dominance of restricted participation emphasised in these data, it is evident that students with ASD continue to struggle to participate in the current educational system. Without greater willingness on the part of schools to accommodate each individual student, and more meaningful involvement of parents and students, mainstream school environments will continue to exert a constraining influence on student participation. All students have the right to an education that is responsive to their individual needs and that enables them to realise their full potential. This thesis reinforces the urgency for action by mainstream schools to accept greater responsibility for their role in enhancing the participation of students with ASD.

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APPENDICES

APPENDIX 1: ETHICAL APPROVAL



THE UNIVERSITY OF QUEENSLAND Institutional Approval Form For Experiments On Humans Including Behavioural Research

Chief Investigator: Ms Caitlin Harrington
Project Title: Inclusion And Exclusion: Mainstream Schooling Experiences Of Students With Autism Spectrum Disorder And Their Parents
Supervisor: Dr Michele Foster, Prof Sylvia Rodger, Dr Jill Ashburner
Co-Investigator(s) None
Department(s): School of Social Work and Human Services; School of Health and Rehabilitation Sciences
Project Number: 2011000190
Granting Agency/Degree: PhD
Duration: 31st March 2014

Comments:

Name of responsible Committee:-

Behavioural & Social Sciences Ethical Review Committee

This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:-

Associate Professor John McLean

Chairperson

Behavioural & Social Sciences Ethical Review Committee

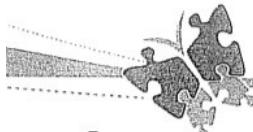
Date

11/3/11

Signature

JPMcC

APPENDIX 2: GATEKEEPER APPROVAL



**Autism
QUEENSLAND Inc.**

Education, Therapy and Support Services

Sunnybank Hills

437 Hellawell Road
Sunnybank Hills Qld 4109
PO Box 354 Sunnybank Qld 4109
PHONE 07 3273 0000
FAX 07 3273 8306

Brighton

136 North Road
Brighton Qld 4017
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Patron: Her Excellency Ms Penelope Wensley, AO

Cairns

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Edmonton Qld 4860
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1 Harbourne Street
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PO Box 1443
Rockhampton Qld 4700
PHONE 07 4926 5188
FAX 07 4926 5199

18 February 2011

Miss Caitlin Harrington
PhD Candidate
School of Social Work and Human Services
The University of Queensland
Brisbane QLD 4072

Dear Miss Harrington

I am happy for you to contact clients of Autism Queensland (parents and children) to invite their participation in the study: *Inclusion and exclusion: mainstream schooling experiences of students with Autism Spectrum Disorder and their families*.

As Autism Queensland does not have its own ethics committee, it will accept the ethical clearance of the University of Queensland.

Yours sincerely

Penny Beeston,
Chief Executive Officer,

APPENDIX 3: PARTICIPANT INFORMATION SHEET FOR PARENTS (on UQ letterhead)

Title: Inclusion and exclusion: mainstream schooling experiences of students with Autism Spectrum Disorder and their parents.

Lay Title: What do students with ASD think about school?

Chief Investigator

Caitlin Harrington

PhD Student

School of Social Work and Human Services

The University of Queensland

Phone: 3365 2093

Supervisors

Dr Michele Foster

Senior Lecturer

School of Social Work and Human Services

The University of Queensland

Phone: 3365 1252

Professor Sylvia Rodger

Head of School

School of Health and Rehabilitation Sciences

The University of Queensland

Phone: 3365 1664

Dr Jill Ashburner

Manager, Research and Development

Autism Queensland

Phone: 3273 0075

Background to the study:

In Australia the majority of students with Autism Spectrum Disorder are educated in mainstream schools. However, students with ASD have diverse and complex educational needs and research suggests that some of these students may experience barriers to their participation and learning in mainstream schools.

What is the aim of the study?

The aim of this study is to explore the schooling experiences of students with Autism Spectrum Disorder and their parents in the mainstream education system in Queensland and the barriers and facilitators to participation from the perspective of students and their parents.

Who is being interviewed?

Parents of students aged 12-18 years with a diagnosis of Autism Spectrum Disorder who are currently attending mainstream school. Students aged 12-18 years will also participate in an interview with parental consent.

Who will be doing the interviews?

The researcher is Caitlin Harrington, a PhD student in the School of Social Work and Human Services, at the University of Queensland. Caitlin is a social worker experienced in working with young people with Autism Spectrum Disorder and their families.

Your involvement in the study:

If you are a parent of a student aged 12-18 years with Autism Spectrum Disorder who is currently attending or previously attended a mainstream school, you are invited to participate in this study. If you consent to participate you will be involved in two interviews. In the first interview an overview of your child's educational history and experiences will be obtained. In the second interview you will be asked about your child's and your own interactions with principals, teachers, teacher aides and peers, the school environment and so on. These interviews will occur at a location and time that is convenient to you. Each interview will take approximately 60-90 minutes. The second interview will be conducted within three months of the first.

It is not anticipated that the interviews will be stressful. However, if you experience stress in any way, the interview will be suspended immediately. If you are comfortable with the idea of resuming the interview at another time, an alternative time can be arranged. If not, you are free to withdraw from the study without fear of penalty. If you do choose to withdraw, the information you provided will be withdrawn from the research, or with your permission it will remain in the study.

A summary of the results of the study will be sent to all participants for their general information at the end of study. In recognition of their participation in the study, each parent will be given \$25.

Your son or daughter's involvement in the study:

With your consent, as well as the consent of your son or daughter, they will be invited to participate in an interview. With this consent, your son or daughter will be involved in an interview about his/her experiences of mainstream school. This will take around one hour to complete. The interview will occur at a location and time that is convenient to your son or daughter. The interview will be audio-taped and then transcribed. They will be given the option to have a parent present during their interview.

It is not anticipated that the interview will be stressful, however if your son or daughter experiences stress in any way, the interview will be suspended immediately. If your son or daughter is comfortable with the idea of resuming the interview at another time, an alternative time can be arranged. If not, your son or daughter is free to withdraw from the study without fear of penalty.

An autism-friendly summary incorporating simple language and visuals will be given to each student at the end of the research process as a way to provide feedback. In recognition of their participation in the study, your son or daughter will be given \$15 in the form of a gift voucher.

How will the information be used?

The information obtained from the interviews will be used as part of a doctoral thesis which will be published by the University of Queensland and stored at the university library. Information will also be used in published journal articles and conference presentations.

How will my privacy be respected?

The information you provide in the interviews will be confidential and only available to the members of the research team. If you agree to participate, your name and other identifying information will not be made available to anyone outside of the research team. Providing you give your consent, the interviews will be tape recorded then transcribed so that there is no identifying information about you in the transcription. Any identifying information about you will be kept separately from the transcripts. Your participation in the research will be kept confidential.

What are my rights and how will they be protected?

Your participation in this study is voluntary and you can withdraw from the study at any time without providing reasons for your withdrawal and without penalty. The information that you provide will be used in this study only and your name will not be

made available to any other party. You have the right to ask questions at any time and details about how you can contact the researcher are available at the top of this information sheet.

This study has been cleared by one of the human ethics committees of the University of Queensland in accordance with the National Health and Medical Research Council's guidelines. You are of course; free to discuss your participation in this study with the Chief Investigator, Caitlin Harrington who is contactable on: 3365 2093 or her principal supervisor, Michele Foster who is contactable on: 3365 1252. If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on: 3365 3924.

Thank you for taking the time to read this information.

Caitlin Harrington

PhD Student

School of Social Work and Human Services

The University of Queensland

Phone: 3365 2093

Email: caitlin.harrington@uqconnect.edu.au

APPENDIX 4: PARTICIPANT INFORMATION SHEET FOR STUDENTS (on UQ letterhead)

Title: Inclusion and exclusion: mainstream schooling experiences of students with Autism Spectrum Disorder and their parents.

Lay Title: What do students with ASD think about school?

My name is Caitlin Harrington. I am studying at University and I am studying student's experiences at school. If it is okay with you and with your parents, I would like to ask you some questions about your experiences at school such as what you do at school, things you like about school and what you might find difficult.

You do not have to be part of the study, it is your choice and it is OK to say no. Even if you say yes, you don't have to answer all of my questions if you don't want to and you are allowed stop at any time if you want to.

If you do choose to talk to me, we will talk for about an hour. If you say it is OK, our talk will be recorded; this will help me to remember things later. You can choose a place where you are comfortable for the interview - such as your house. You can choose to have a parent with you during the interview if you would like to.

The information you tell me will only be used in the study and your name will not be used. I will not tell people anything that you tell me without your permission. If you choose to participate you will be given a \$15 gift voucher to say thank you for talking with me. You can ask me more questions about the study whenever you like.

Thank you,

Caitlin Harrington

PhD Candidate

School of Social Work and Human Services

The University of Queensland

Phone: 3365 2093

Email: caitlin.harrington@uqconnect.edu.au

APPENDIX 5: PARENT CONSENT FORM (on UQ letterhead)

Title: Inclusion and exclusion: mainstream schooling experiences of students with Autism Spectrum Disorder and their parents.

Lay Title: What do students with ASD think about school?

Chief Investigator:

Caitlin Harrington

PhD Student

School of Social Work and Human Services

The University of Queensland

Phone: 3365 2093

Supervisors:

Dr Michele Foster

Senior Lecturer

School of Social Work and Human Services

The University of Queensland

Phone: 3365 1252

Professor Sylvia Rodger

Head of School

School of Health and Rehabilitation Sciences

The University of Queensland

Phone: 3365 1664

Dr Jill Ashburner

Manager, Research and Development

Autism Queensland

Phone: 3273 0075

I have read the Participant Information Sheet and I hereby consent to be interviewed as part of the research project. By signing this form I acknowledge that:

- I have read and understood the Participant Information Sheet and my questions about the research have been answered to my satisfaction.
- I understand the nature and purpose of the study, any potential risks and what is required of me by agreeing to be involved.
- I agree to be interviewed on two occasions and for these interviews to be tape recorded and transcribed.
- I hereby consent to the participation of my son/daughter in the study which I understand will involve an interview about their experiences in mainstream school.
- I have discussed this study with my son/daughter who also freely consents to participate in the study.
- I understand that all information and personal details gathered during the course of this research will remain confidential, will be stored securely and I will not be identified in any information published from this study.
- I understand that only the research team will have access to my information and no personal details or any information that I provide will be discussed with any other person or passed onto any other person.
- I understand that my participation in this study is voluntary and that I am free to withdraw without penalty at any time and that I do not have to provide reasons for withdrawing.
- I understand that my son/daughter's participation in this study is voluntary and that they are free to withdraw without penalty at any time and that they do not have to provide reasons for withdrawing.
- I am aware that I may ask further questions about the research at any time.

Participant Name:.....

Participant Signature:.....

Date:.....

Witness Name:.....

Witness Signature:.....

Date:.....

APPENDIX 6: STUDENT CONSENT FORM (On UQ letterhead)

Title: Inclusion and exclusion: mainstream schooling experiences of students with Autism Spectrum Disorder and their parents.

Lay title: What do students with ASD think about school?

- I
(Please write name here)

have read the Participant Information Sheet and understand what the study is about and how I will be involved.

- I agree to answer some questions about my experiences of mainstream school in an interview and for the interview to be tape recorded and transcribed.
- I understand that Caitlin will not tell anyone anything that I tell her about myself unless I say it is OK first.
- I understand that I have volunteered to be involved and that I am allowed to stop being in the study at any time without giving a reason and without negative consequences.
- I understand that I can ask more questions at any time.

Signed:----- Date: -----

(Student)

Signed:----- Date: -----
(Witness)

APPENDIX 7: SOCIAL STORY ABOUT THE RESEARCHERS VISIT



This is Caitlin



Caitlin is a university student



Caitlin drove to your house in her car



Caitlin would like to ask you some questions about school



Is that okay with you?



Caitlin will speak to you for about one hour



Caitlin has her 'stop' card with her

You can use this to say 'stop'

break time



Caitlin has her 'break time' card with her
You can use this to say you need a break.



You can ask Caitlin questions any time you want



It will be okay to speak to Caitlin

APPENDIX 8: PARENT INTERVIEW GUIDE ONE

Thank you for agreeing to participate in the interview today. This is the first of two interviews. The purpose of today's interview is to gain your perspective on your child's experiences of participation in the mainstream education system across primary and secondary school. I will be asking you some questions in order to obtain a general overview of your child's educational history and experiences of inclusion and exclusion.

A second interview will occur in the next month or so at a place and time that is convenient to you. The purpose of the second interview will be to obtain more in-depth and specific information on your child's experiences in the mainstream education system in primary and secondary school.

Today's interview will be tape-recorded with your consent and transcribed. Your name will not be used in the transcription or in the publishing of results. The interview will last approximately 60-90 minutes. Please let me know if you would like a break during this time. You do not have to answer all of my questions and you may withdraw at any time without penalty. If you do choose to withdraw, the information you have supplied will be removed from the study, or kept in the study with your permission.

To say thank you for your participation in the study you will be given \$25 at the end of the second interview.

Do you have any questions before we begin?

I would like to begin now by asking you to confirm your consent to this interview. **FILL IN CONSENT FORM**

Background and personal information

- Name:
- Age:
- Ethnicity e.g. Do you speak a language other than English:
- Marital status:
- Highest level of education:
- Employment status:
- If employed, how many hours per week do you work?
- (If partnered) what is your partner's highest level of education?
- (If partnered) what is your partner's employment status? How many hours per week?
- How many children do you have? What are their ages?
- Diagnosis and date of diagnosis?
- Do they have any co morbid diagnoses?
- Do they take Medication? Any recent changes to their medication?

This interview is divided into four sections. In each section I will be asking you some specific questions relevant to the aims and focus of my research. Let's begin.

Section 1: Tell me about your family...

- Diagnosis
- Pre-school experiences

Section 2: In this section of the interview I would like to hear your perspective on your child's experiences of participation in primary school and the barriers and facilitators to their participation. When I say 'participation' I mean "taking part and being included in both the academic and social life of the school". A barrier is defined as anything that has acted as an obstacle to your child's participation or inclusion and learning in terms of social and academic life. A facilitator is defined as anything that has acted to enhance the participation or inclusion and the learning of your child in terms of social and academic life.

Take me back to when your child first started school; tell me what it was like trying to find a school for them...

- Were there obstacles to finding a suitable school?
- Once you had found a school and enrolled in it, how did your child experience the transition to primary school? E.g. Was it smooth or rocky?
- What was your role during this transition?
- What was the school's role? E.g. what staff members were involved?
- How did you and your family experience the transition?
- Did your child receive an ascertainment level? Did they have an IEP? What supports were recommended? How often were they supposed to be reviewed? Were the supports provided? Why, why not?

Tell me about your child's educational arrangements during the early years of primary school...

- Where did they go to school?
- What kind of support did they receive? Who did they receive it from? Did they have an IEP? Was it followed? Why, why not?
- How would you describe their level of participation at this time? What did they participate in?—e.g. Academically? During class? The curriculum? Socially? Lunchtime? After school? Were there aspects of school they didn't they participate in? Why, why not?
- Did they face any barriers to their participation?

A barrier is defined as anything that has acted as an obstacle to your child's participation and learning in terms of social and academic life. Examples could be: school culture, school resources, school discipline policies, level of home/school collaboration, parents exercising agency, child exercising agency, physical school environment, attitudes and behaviour of school principal, teachers, teacher aides and peers.

- If so, can you tell me about these barriers? How were these experienced by your child? How were they experienced by you and your family? Were there impacts on your child? on you? on the family?
- Are there particular things that facilitated their participation at that time?

A facilitator is defined as anything that has acted to enhance the participation and learning of your child in terms of social and academic life. Examples could be: school culture, school resources, school policies, level of home/school collaboration, parents exercising agency, child exercising agency, physical school environment, attitudes and behaviour of school principal, teachers, teacher aides and peers.

- If so, can you tell me about these? How were these experienced by your child? How were they experienced by you and your family?

Tell me about later primary school...

- How were things then?
- Were they different to early primary school? How?

Provide a summary of what the parent has said so far...

- Looking across primary school, when were things working well? E.g. your child was participating/was included. Why do you think they were working well? Who was involved?
- When weren't things working so well? E.g. child was not participating or was excluded. Why do you think they weren't working so well? Who was involved?

Section 3: Now I would like to explore your perspective on your child's experiences of participation in high school and the barriers and facilitators to their participation.

Can you start by telling me about your child's transition to high school...

- Was it smooth or rocky? Was there preparation?
- What was your role during this transition?
- What was the school's role? E.g. which staff members were involved?
- What supports were supposed to be provided by the school? Were they?
- How did your child experience this transition? How did you and your family experience the transition?

Tell me about the past few years of high school...

- How have things been?
 - Were they different to the experiences in primary school? How?
 - How would you describe their level of participation during the early years of high school? What did they participate in?—e.g. Academically? During class? The curriculum? Socially? Lunchtime? After school? Were there aspects of school they didn't they participate in? Why, why not?

- Did they face any barriers to their participation? If so, can you tell me about these barriers?
- How were these experienced by your child? How were they experienced by you and your family? Were there impacts on your child? on you? on the family?
- Are there particular things that facilitated their participation at that time? If so, can you tell me about these?
- How were these experienced by your child? How were they experienced by you and your family?

Tell me about your child's current educational arrangements...

- Where do they go to school? What grade are they in? What kind of supports do they receive? IEP? Where do they receive supports: In-class or removal to special education class?
- Tell me about what your child participates in at school? –e.g. Academically- During classes? The curriculum? Socially – at lunchtime? Friendships? After school? Are there aspects of school that they don't participate in? Why, why not?
- Does your child currently face any barriers to their participation? If so, can you tell me about these barriers? How are these experienced by your child? How are they experienced by you and your family? Impacts?
- Are there things that facilitate your child's participation? If so, can you tell me about these? How are these experienced by your child? How are they experienced by you and your family?

Section four: I would like finish up the interview by getting an overall summary of your child's schooling.

-Looking across the whole of your child's schooling what stands out to you?

-Were there any turning points?

-When were things working well? Why do you think they were working well? What are the reasons? Who was involved?

-When weren't things working so well? Why do you think they weren't working so well? What are the reasons? Who was involved?

-Is there anything else you would like to add?

APPENDIX 9: PARENT INTERVIEW GUIDE TWO

In today's interview we will discuss your child's mainstream school experiences in more depth. This is a chance for you to say anything you didn't have a chance to say last time it is also a chance for me to clarify some of the things you spoke about last time.

The interview will be tape-recorded with your consent and then transcribed. Your name will not be used in the transcription or in the publishing of results. The interview is broken up into four sections and will last approximately 90 minutes. Please let me know if you would like a break during this time. You do not have to answer all of my questions and you may withdraw at any time without penalty. If you do choose to withdraw, the information you have supplied will be removed from the study, or kept in the study with your permission. To say thank you for your participation in the study you will be given \$25 at the end of the interview.

Do you have any questions before we begin?

Section 1: Change:

- Have there been any changes in your child's education or has anything eventful happened since last time we spoke?
- Is there anything you would like to add or expand on that we discussed last time?

Section 2: Clarification:

- Looking at the timeline what stands out to you? What do you notice about your child's experiences?
- What do you identify as inclusion and exclusion experiences?
- Do you think your child has had an inclusive experience? When? What was happening then?
- When has your child had an exclusive experience? What was happening then?
- Has the education system let your child down? How?
- (If they have described it as 'too late' for their child) what makes you think it's too late? At what point did it become too late? What would have helped at this point? *E.g. better teacher, more funding, smaller class size.*
- What would have improved or could still improve your child's level of participation in school?
- In what ways have you tried to advocate for your child? Were there barriers to your advocacy efforts? What were they? Are there things you would do differently? What would you repeat/do the same?
- What has been the psychological, social and financial impact on you as a carer and on your family members and relationships?
- Did experiences in primary school shape/colour your child's experiences in high school? How? Has there been a cumulative effect? How do you think the expectations on students differ in primary vs high school?

Section 3: Future:

- Looking at the timeline what do you think is likely to be the future of your child's education? *E.g. Higher Education, employment etc.*

- Do their experiences of education have implications for how you think they will participate as an adult in society? What kind of implications? *E.g. financial, social etc.*

Section 4: Ideal:

- If you woke up tomorrow and your child was receiving a fully inclusive education, what would that look like? Who would be involved? *E.g. what would teachers be like? Principals? Teacher aides? Peers? School culture? Environment? Communication between home and school? Curriculum?*
- What kind of education should children with ASD receive? And where should they receive it?
- What advice would you give other parents about supporting their child's education at mainstream school?
- Are there any final comments you would like to make?

APPENDIX 10: STUDENT INTERVIEW GUIDE

My name is Caitlin and I am a university student. I'm here to ask you some questions about your experiences at school. I am asking 8 other kids like you the same questions. I want to know what you think is good and bad about school so I can help other kids with autism to learn in schools. Your mum/dad gave their permission for me to talk with you. Is it OK if I ask you some questions? Is it OK if I record this interview? I will write out some notes from it later on when I have more time. I will also take some notes now to help me remember what you say. The interview will take approximately 60-90 minutes. I will ask you if you need a break at any stage. You don't have to answer all of my questions if you don't want to and you can stop any time if you want to, you just have to say 'stop' or hold up this stop card (show stop card to the student). The information you tell me will only be used in the study and your name will not be used. I will not tell people anything that you tell me without your permission. You will be given \$15 at the end to say thank you for helping me. You can ask me more questions about the study whenever you like. Do you have any questions before we begin?

Interview questions

Tell me about yourself

- How old are you?
- What are some things you like to do?

Tell me about school

- What school do you go to?
- Do you wear a uniform? What's it like? How find wearing a uniform? E.g. Is it good, or not so good?
- What grade are you in at school?
- What classes do you do at school?
- How do you get to school in the morning? E.g. Bus, parent drives you.
- What do you do when you get to school, before the bell rings and you have go to class?

Tell me about during class

- What does your classroom look like?
- What does it sound like? E.g. is it loud or quiet?
- Where do you sit?
- What do you do during class?
- Is there anything you don't get to do?

-What are your classmates like? Do you get along with them? How do they act towards you?

-What are your teachers like? What do they do during class? How do they act towards you? What do they do that helps you to learn? What do they do that doesn't help you to learn?

-Is there a teacher aide? What do they do in class? How do they act towards you? What do they do that helps you to learn? What do they do that doesn't help you to learn?

-What is your school principal like? How do they act towards you?

Tell me about what it's like when you're going from one class to the next one

-Do you have to change classrooms during the day?

-Are there different kids in each class?

-How easy/hard is it changing classes during the day? E.g. good, not so good.

Tell me about lunchtime

-What do you do during break?

-Where do you go?

-What does the playground look like? What do you like/not like about the playground?

-What does the playground sound like? E.g. Loud, quiet.

-What do the other kids do during break?

-What do you like about break?

-What don't you like about break?

-Some of the kids I have talked to have been in trouble at school for all sorts of reasons. I wonder if this has ever happened to you... Have you ever been in trouble at school? What was it for? What happened? How did you feel? (offer feeling cards)

-Have you ever been sent home from school? Or not allowed to attend school? What happened? How did you feel?

-Have you ever left school early or refused to go to school? Why?

Tell me about after school

-What do you do?

-Are there after school activities at your school? Do you get involved in them? E.g. Computer club, sports.

-Do you have homework? Do you do your homework? Do you like doing homework? Is there anything you find hard when you're doing homework?

-Do you go on school camps?

-Do you play with friends?

Summary questions:

-So overall, what do you like about school?

-What don't you like about school?

-Do you think you fit in at school?

-When do you feel like you fit in? -e.g. is it with peers or in class

-Are there times when you feel like you don't fit in?

-What are the worst parts about school?

-Are there particular lessons or teachers you don't like? Why?

-Are there particular activities or places you don't like? Why?

-What would make school more enjoyable for you?

-What helps you to learn best?

-What else helps you during the school day?

-What needs to change about school?

-Is there anything else that is good or not so good about school and why?

THANK YOU.

APPENDIX 11: VISUAL INTERVIEW SCHEDULE

(STUDENTS NAME)

TASK	TICK FOR FINISHED
TALK ABOUT BEFORE SCHOOL	
TALK ABOUT DURING SCHOOL	
TALK ABOUT AFTER SCHOOL	
YOU ARE FINISHED. WELL DONE!	

APPENDIX 12: PARTICIPATION TRAJECTORY GRID

Year	Individual child context	Family context	Social/ community context	School context	Historical context	Level and quality of school participation	Parent actions
1995	Declan was born.	Mother Father					
1996							
1997		Sister is born.					
1998							
1999				Kindergarten: <i>“Raising red flags”.</i>		Often playing by himself, he refused to sit with groups of children.	Hayley did positive parenting course.
2000				Preschool Primary school 1: Teacher implied Hayley had bad parenting skills. Teacher saw Declan as “naughty”. Moved to primary school 2.			Hayley moved Declan to a different state school.
2001			Paediatrician : felt Declan had ADHD. Speech therapy. OT.	Grade 1 Teacher suggested Hayley take Declan to paediatrician. - “They didn’t understand autism” e.g. his social and		Declan was at the back of the class not doing any work. School: “Forced him to do things the other kids did and he	Hayley didn’t think Declan had ADHD so she kept investigating, did elimination diet with Declan and other

				sensory issues. No funding for ADHD.		<i>wouldn't be very happy about that</i> ".	therapies.
2002				Grade 2 Teacher was older and more experienced “she dealt with it”			
2003	Declan on Ritalin. “Turned him into a zombie”.		Paediatrician at Mater: Also felt he had ADHD.	Grade 3 Teacher suggested Declan might be autistic. “She could cope with Declan” She adapted – “she got quite a bit of work out of him”.		Declan was doing his work on the Dex.	
2004	Declan refused to do handwriting. Declan had a problem with the school.			Grade 4 Teacher: was academically driven and would send Declan out of the class if he didn’t do his work. Deputy Principal: Declan said he was mean. The teacher screwed up his written work.		Declan wasn’t attempting to do things if he thought he would get the answer wrong. Declan would be sent home a lot. Ran away from school. “He’d be sitting outside the classroom a lot of the time not actually doing the work”. “They wouldn’t try and get him	Hayley always worked really closely with the schools.

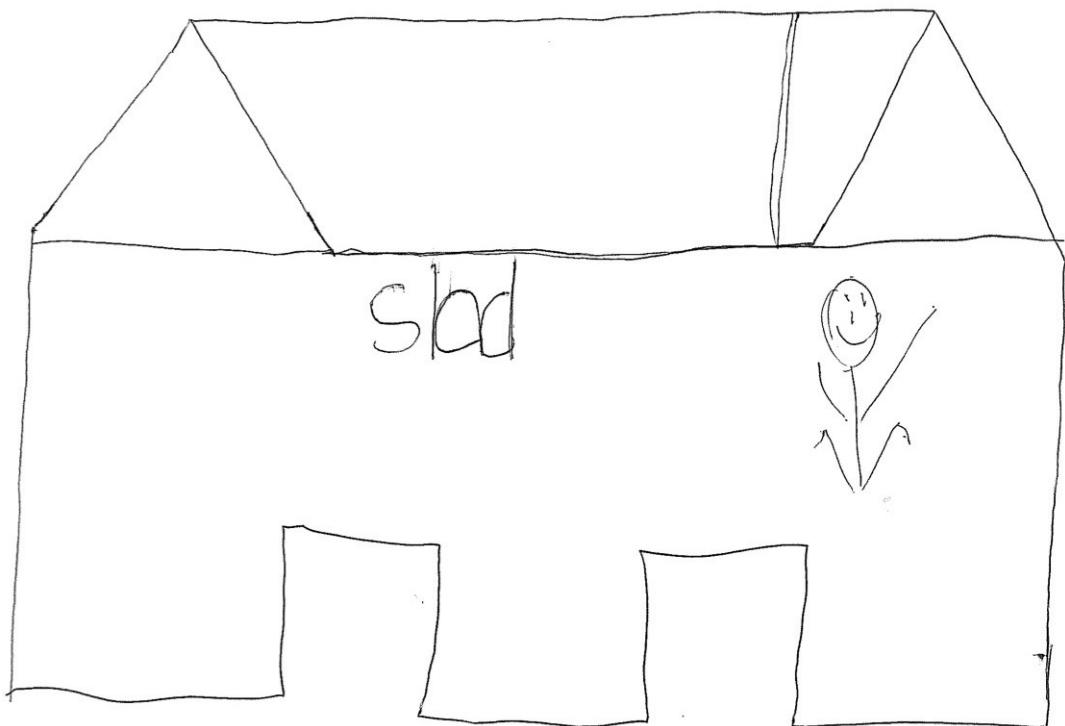
						<i>back in class, they'd just withdraw him".</i> Declan was being bullied and he would be goaded into doing the wrong thing.	
2005	Declan was diagnosed with ASD.	Paediatrician at RCH diagnosed Declan. AQ involved.	Grade 5 Teacher: more experienced and understanding of special needs. <i>"The teacher could handle him".</i>	Education Queensland: Inclusive Education Statement 2005 introduced.	<i>"The school would refuse to let Declan come to school unless he had his medication".</i> He wasn't allowed to go on school camp unless Hayley stayed close by. Declan was bullied.	Hayley put in reward systems in place to get him to go to school. Hayley went and stayed close by to the camp. Hayley linked in with AQ.	
2006	Declan was taken off Ritalin. Declan placed on herbal medication. <i>"Declan hated school and had withdrawn himself from school".</i>	Psychometric testing: assessed as gifted but 'at risk'. Psychiatrist was concerned Declan might develop a conduct disorder.	Grade 6 In-class time with teacher aide. Incident at the school where Declan pointed a letter opener at a teacher. Disciplinary approach to behaviour. Teacher was inexperienced, young and scared of Declan. Independent school:	Declan was excluded for 12 months from the school. He was enrolled in an alternate education program. Independent school: Hard for him to make friends. <i>"He did get a sense of achievement to a certain degree".</i> <i>"He was</i>	Parents hired a solicitor to fight the exclusion but were unsuccessful. Hayley home schooled Declan for six weeks. Hayley moved Declan to an independent school.		

				<p>Small group of kids.</p> <p>Could wear his own clothes.</p> <p>No boundaries, loose structure.</p> <p>Art therapy, massage therapy.</p> <p><i>"They were very caring".</i></p> <p>Expensive.</p>		<p><i>much happier there".</i></p> <p>He didn't do the academic tasks.</p>	
2007				<p>Grade 6 repeated</p> <p>Independent School:</p> <p>Missed grade 7 concepts.</p> <p>AQ:</p> <p>2 days per week</p> <p><i>"AQ was the best thing that's ever happened to us".</i></p> <p>Social skills.</p> <p>Community visits.</p> <p>Environment where people understood and cared.</p>		<p>AQ: <i>"He learned an awful lot at AQ".</i></p> <p><i>"He felt he belonged there".</i></p>	Hayley felt his education was slipping and that the school was too expensive so she pulled him out.
2008				<p>Grade 8</p> <p>Private school:</p> <p>Sensory issues with school socks.</p>		<p>Withdrew himself from sport.</p> <p><i>"He performed really quite well"</i></p>	Hayley moved Declan to private school.

				<p>Difficulty changing uniforms for sport.</p> <p>Pastoral care = good.</p> <p>Special ed department case manager helped transition to high school. <i>“Paved the way”</i>.</p> <p>IEP social goals.</p> <p>AQ:</p> <p>2 days per week</p>		(academically).	
2009				Grade 9 Private school & AQ (1 day per week).			
2010				<p>Grade 10</p> <p>Private school:</p> <p>Teachers found Hayley's talk helpful in educating them on ASD.</p> <p>A lot of the teachers are more caring.</p> <p>Good Home Ec. teacher.</p> <p>Offered a quiet place to watch school assembly away from the noise.</p>	<p>Declan went to camp for the whole month like the other students.</p>	<p>Hayley has a lot of contact with the teachers and the school.</p> <p>Hayley went and did a talk with the staff at the school about what it is like to have a child with ASD.</p>	

2011	<p>Declan is suicidal.</p> <p>Declan applied for and won a defence technical scholarship .</p>		<p>CYMHS this year.</p> <p>School-based traineeship in I.T. one day per week.</p>	<p>Grade 11 Private school:</p> <p>Transition to year 11 was difficult.</p> <p>QSA: all peers are judged by the same criteria so they can't modify the content for Declan.</p>		<p>He wasn't doing any work in class.</p> <p>He changed his mind and is now doing work in class.</p>	
Future			<p>Will be 'different' in society.</p> <p>Very fixed views, quite extreme, may be marginalised as a result.</p> <p>Hopeful that he will be able to live independently.</p>	<p>Hopes he finishes year 12</p> <p>Hopeful he will get a traineeship and transition into fulltime work</p>			

APPENDIX 13: PAUL'S DRAWING OF LIFE AT SCHOOL



"This is me next year when the bullies are gone" (Paul).

APPENDIX 14: EXAMPLES OF THE STEPS OF ANALYSIS

Example of coding framework: Parent data

PERCEPTIONS OF THEIR CHILDREN'S PARTICIPATION EXPERIENCE

- Social participation
 - Friendships
 - Bullying
 - Extra-curricular
- Academic participation
 - Engagement in learning
 - Exclusions and suspensions
 - Achievement

PERCEPTIONS OF THEIR CHILDREN'S EXPERIENCE OF SCHOOL STAFF

- Teachers
- Leadership personnel

PERCEPTIONS OF CHANGES IN THEIR CHILDREN'S PARTICIPATION EXPERIENCE

OVER TIME

- Transition to high school
- Experience in autism-specific school

PARENT EXPERIENCE OVER TIME

- Advocacy
- Impact on their lives

Extract from a thematic chart: Parent experience

Participant (Pseudonym)	Code: impact on their lives	Dimensions of this code
Julia	<p><i>"You're spending 70-80% of your time trying to get somebody to listen to you to get your kid settled that you've only got 10% left here, and 10% left there [referring to her two other children] and nothing left over for you".</i></p> <p><i>"It's had a huge financial [impact]. I think at one stage we thought we were going to lose everything, just lose everything. We'd just bought a new house and we had to sell it, cause we couldn't do it anymore which causes more stress".</i></p> <p><i>"There was no support from family, none ...they're just not interested, and it's our problem sort of thing".</i></p>	Time-consuming nature of advocacy; impact on siblings Financial impact; housing instability Lack of family support
Sarah	<p><i>"I'm probably going to have to do some sort of hard labor type work you know like packing shelves, something which pays high to bring in some money... but I can't afford to be a youth worker anymore. They don't pay enough for me to be able to bring in enough money for the hours at all and the volunteer hours that you put in in a job like that are big as well".</i></p> <p><i>"We bought this house cause of the \$21, 000 grant and now it's too expensive for us because we've only got one person working and the prices of houses have dropped so we're just between a rock and a hard place. We have to try and keep this house until the prices increase again so that we can then sell and go somewhere we can afford but at the moment we can't afford to lose on it because we won't be able to live at all".</i></p>	Change of career Loss of income; housing instability
Hayley	<p><i>"I was really sorry at one stage that I got a mobile phone cause that meant I was always contactable...in later years like I think from year four on I was probably picking up and taking him home quite a bit".</i></p> <p><i>"It must have been year five I think and he wasn't allowed to go on camp unless I went and stayed close by so I had to go and stay in a caravan park down the road from the place at Kenilworth and they would call me if I needed to go and pick him up".</i></p> <p><i>"I spend an inordinate amount of time going to the</i></p>	Frequent calls to collect child On-call Time consuming

	<p><i>school and doing stuff at the school you know, to the point where sometimes it puts my role here in jeopardy. I think I said last time that you have to have really understanding employers you know because you couldn't function, I couldn't function in a normal sort of job".</i></p> <p><i>"You know very much she thinks she's not getting the attention that she should get and sometimes she wasn't because you just physically couldn't give it you know you had to respond to a crisis and so she was justified in feeling that".</i></p> <p><i>"When they both went to the same school she'd get tagged with his brush or you know everybody would tell her all the bad things Declan did and not give her a chance to be her own person".</i></p>	<p>Need flexible employers</p> <p>Negative impact on sibling</p> <p>Negative impact on sibling</p>
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Example of a memo: Parent experience – impact on their lives

There were numerous impacts on parents' lives. For the majority these were negative impacts, for example it was time consuming (Julia), most parents reported constant phone calls and having to collect their children before finishing time (Anna, Hayley, Sarah, Glen, Julia, Laura). Most commented on the impact on their careers, for example two parents gave up work entirely (Philip & Julia), two changed from professional careers to more flexible retail jobs (Anna & Sarah) and some reduced their hours of work (Jemma, Laura). Parents who were still employed emphasised the need to have an understanding employer and flexible working arrangements so that they could respond to school issues when they arose (Hayley & Jemma). The consequence of reduced ability to work was reduced income for families and in two cases parents reported being on the brink of financial ruin at some stage (Julia & Sarah). Parents also commented on the impact on their mental health and relationships with their families of origin and their other children. Overall what this data indicates is that parents lives were altered significantly by their children's participation experiences. Create theme: altered lives.