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DEPARTMENT OF SOCIAL WORK AND SOCIAL PLANNING

THE EFFECTS OF THE DISABILITY STANDARDS FOR EDUCATION ON THE EXCLUSION OF CHILDREN WITH AUTISM SPECTRUM DISORDERS FROM MAINSTREAM SCHOOLING

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July 2011

THIS THESIS IS SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS OF THE DEGREE OF BACHELOR OF SOCIAL WORK (HONOURS)

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SYNOPSIS

The National Disability Standards for Education that accompanied the Disability Discrimination Act (1992) were implemented in 2005. The aim of this legislation was to promote inclusive education for all; however limited research in this area has shown that exclusions of children with Autism Spectrum Disorders (ASD) from mainstream schools are still occurring. This South Australian study employed a mixed methods approach to address three research questions; to explore, from the perspective of families, the levels to which children with ASD in SA are being excluded from mainstream schools; to identify whether parents' experience has differed since the implementation of the Disability Standards for Education (2005) and determine how familiar parents are with the legislation; and to explore, from the perspective of families of children with ASD, how their experiences are in keeping with the principles of inclusive education which underpin the DDA (1992). Consistent with previous research, responses from parents indicated a plethora of issues that continue to face children with ASD in accessing mainstream education. The lack of specific research in this area highlights the need for further research both on a larger scale and in different states.

ACKNOWLEDGEMENTS

I would like to thank and acknowledge all those who assisted and supported me through this study.

Firstly I would like to thank my Honours supervisor, Associate Professor Fiona Verity, whose expert guidance was invaluable in assisting me to better my work and develop ideas. I am immensely grateful for her encouragement and ability to break down seemingly overwhelming ideas in to manageable tasks! I would also like to thank other members of the Flinders University staff, in particular Dr Keith Miller, who went out of their way to assist me in completing this study.

To my wonderful family and friends, a huge thank you for your love and support throughout this process. Very special thanks to my mum, who provided me with endless advice and always made time to answer my constant stream of questions. Her support was amazing throughout. And a big thank you to my partner Rupert, who did everything he could to support and encourage me. I could not have done it without you both.

To all the families who volunteered their time to participate in my study, I cannot thank you enough for investing so much time and passion in to my research. I feel truly privileged to have had you share such personal stories of struggle, heartbreak, triumph and hope.

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1.1. Introduction

From 2005 to 2009, the number of funded students with disabilities in Australian schools increased by over 20 per cent, to more than 164,000 students (Garret & McLucas 2011). The number of new diagnoses of Autism Spectrum Disorders (ASD) in South Australia rose from 74 in 1994 to 720 in 2009, creating demand for quality education services responsive to the needs of students (Ministerial Advisory Committee: Students with Disabilities 2010). With this rate of diagnosis predicted to increase dramatically in the next few years (Department of Education, Employment and Workplace Relations 2009), and early intervention and teacher development programs such as the Federal Government's 'Helping Children with Autism Package'[1] being in place for two years, it is crucial to see what the effect has been within schools.

This study considers parents' experiences of the education of their children with ASD within formal education systems. In South Australia, all children aged between six and sixteen years are entitled to attend school full-time (Education Act 1972) and national Disability Standards for Education aim to ensure every student has the same opportunity regardless of disability.

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[1] The program was developed to alleviate the high level of need for support and services for children with ASD (Australian Government 2010). It recognises the 'importance of diagnosis and early intervention treatments and services for children with Autism Spectrum Disorder, along with the need for positive partnerships between their families and schools' (Australian Government 2010, para. 2). Running from 2008-2012, the Positive Partnerships program delivers professional development for teachers, along with workshops for parents, aiming to build stronger relationships between families and schools to enable better schooling outcomes for children with ASD.

However, whilst this is the formal policy, recent reports identify children with disabilities frequently being excluded from local kindergartens and schools (National People with Disabilities and Carer Council 2009). Figures from the Australian Institute of Health and Welfare (2006) showed that '63 per cent of school children with disabilities experienced difficulty fitting in at school' (cited in Innes 2010). Children with ASD are reported to be over twenty times more likely to be excluded than those without special educational needs (Humphrey 2008).

1.2 Policy and legislation

The *Education Act 1972* (SA) states that all school enrolled children aged between six and sixteen are required to attend full time, as per instruction provided by the school for the child (Department of Education and Children Services 2009). The *Disability Discrimination Act 1992* (Cwlth) (DDA), informed by human rights values[2], also applies in all Australian states and territories and is upheld and monitored by the Australian Human Rights Commission (Kerridge 2006). The DDA seeks to:

- Eliminate, as far as possible, discrimination against people on the grounds of disability
- Ensure that people with a disability have the same rights before the law as the rest of the community

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[2] In 2008 Australia ratified the United Nations Convention on the Rights of Persons with Disabilities, which adds detail in Article 24 relating to the rights of people with disabilities and education, specifically around people with disabilities having the right to access inclusive education on the same basis of those without a disability and not be excluded (Australian Government 2010; United Nations General Assembly 2008).

- Promote community recognition and acceptance of the principle that people with a disability have the same rights as the rest of the community (Disability Discrimination Act 1992, p. 1).

The Disability Standards for Education, developed under the DDA to make the legal obligations of the Act clear, were implemented as a legal requirement for Australian educational authorities in August 2005 (Department of Education and Children's Services 2007, p. iii; Department of Education, Employment and Workplace Relations 2010; Ministerial Advisory Committee: Students with Disabilities 2010). These Standards act concurrently with State laws and legislate that students with a disability must be able to participate in all school programs, utilise services and facilities and gain admission on an equal level with students without disabilities, as well as the same access to educational opportunities and choices (Department of Education and Children's Services 2007; Department of Education, Employment and Workplace Relations 2010; Kerridge 2006).

The Standards aim to ensure that every student has the same choices and opportunities, regardless of disability. Education providers are also required to ensure that students are free to learn without being subject to harassment or victimisation (Department of Education, Employment and Workplace Relations 2010). The Standards outline the compulsion for equal access for all students, with the Department of Education and Children Services (DECS) using Moore et al.'s definition of 'access' in their guide to implementing the Standards, as referring to 'a learner being enrolled and attending at a site. It is affected by withdrawal from class, suspension and exclusion' (cited in Department of Education and Children's Services 2007, p. 6; Moore et al. 2004).

Of particular importance in the DDA is Section 22: Education, which states:

> It is unlawful for an educational authority to discriminate against a student on the ground of the student's disability:
>
> - by denying the student access, or limiting the student's access to any benefit provided by the educational authority; or
> - by expelling the student; or
> - by subjecting the student to any other detriment (Disability Discrimination Act 1992, p. 21).

Particularly pertinent is the second dot point above, as it is clearly laid out in law that it is illegal to expel or exclude a student because of their disability, or to discriminate at any point during the suspension or expulsion process (Kerridge 2006). Importantly, the Standards seek to protect any person with a disability from discrimination, even if that person has been expelled from the school (Kerridge 2006, p. 3).

The role of educational providers is to ensure supports are in place for students to participate in all aspects of the school program without experiencing discrimination. This entails making any required changes to allow equal access, participation and achievement (Department of Education and Children's Services 2007, p. 8). In the Standards this is termed 'reasonable adjustment' and takes into account student needs and benefits versus the costs for the institution. If it is found that this places an unreasonable burden on the institution in regards to resources needed then it can be termed 'unjustifiable hardship', in which case the school is within its legal rights to refuse (Department of Education and Children's Services 2007; Department of Education, Employment and Workplace Relations 2010). If someone believes an educational provider is not carrying out its obligations under the DDA, they can formally complain to the Human Rights and Equal Opportunity Commissioner (HREOC) (Kerridge 2006). Exceptions occur when the school can prove that carrying out these obligations is too difficult, or when they are required to ‘discriminate to protect the health and welfare of that person’ (Kerridge 2006, p. 6). Between the implementation of the DDA in March 1993 and June 2009, there were 10,217 disability discrimination complaints made under the Act, as well as complaints made under State and Territory laws (Australian Government 2010), of which nine per cent related to education (Australian Government 2010).

1.3 Factors leading to recognition of the need for Disability Standards for Education

Prior to the development of the Standards, frequent exclusion of children with disabilities from local kindergartens and schools was still taking place despite legislation in 1992 making disability discrimination in schools illegal (Flynn 1997; National People with Disabilities and Carer Council 2009). Reports into this indicated a plethora of barriers to inclusion. This was a result of structural issues (such as insufficient funding and inadequate complaint mechanisms), student needs not being recognised, and conscious and unconscious discrimination by educators and/or the school community.

Insufficient funding meant that many schools struggled with practical issues in implementing necessary measures for inclusion and there was limited additional funding for behavioural support (Flynn 1997; Ministerial Advisory Committee: Students with Disabilities 2001b). Students’ needs were not being recognised and parents were often forced to act as both support staff and advocates on behalf of their children (Flynn 1997). Hall (1997) identified a disparity between education providers’ desire to provide what children needed and an understanding of those needs, as well as difficulties around the diagnosis itself. Difficulties in early diagnosis before a child began school often resulted in children being enrolled without the required supports being in place (Flynn 1997; Hall 1997).

The policy shift over the last twenty years, away from segregating students with a disability, has resulted in approximately 93 per cent of all students with a disability now being enrolled in mainstream schools (albeit often in special classes or special units within those schools) (Ministerial Advisory Committee: Students with Disabilities 2001b; Department of Education and Children's Services cited in Ministerial Advisory Committee: Students with Disabilities 2010). For example, approximately 3400 students with ASD registered with Autism SA are enrolled in Government, Catholic or Independent education services, with 57 per cent enrolled in mainstream classes (Autism SA 2010 cited in Ministerial Advisory Committee: Students with Disabilities 2010). Seventy-eight per cent of students with Asperger Syndrome attend mainstream classes, as compared with 40 per cent of those with Autism disorder (Ministerial Advisory Committee: Students with Disabilities 2010). The Ministerial Advisory Committee: Students with Disabilities (MAC:SD) members attribute this to the levels of intellectual disability associated with an Autism diagnosis, meaning greater likelihood of accessing specialised education settings (Ministerial Advisory Committee: Students with Disabilities 2010).

Flynn's 1997 report indicated that although there was 'general goodwill' within senior education authorities around inclusion policies, principals have varied in their support regarding integration. There was opposition from some individual principals who did not want to adapt their practices, or were not sufficiently familiar with legislation (Flynn 1997). Other reports show children being excluded as a result of standing up against reportedly widespread bullying, as well as experiencing other barriers such as the attitude of other parents in the school community and the complaints processes (few parents made formal complaints due to their costly and time consuming nature) (Flynn 1997). Of those who did complain, the large majority had a negative experience as a result, with their children being further discriminated against and forced to leave.

1.4 Current study justification

Since the 1992 implementation of the DDA, there has been research exploring inclusion in mainstream schooling, yet little has been conducted post 2005 when the Standards were implemented. There is no current research on the Standards' effectiveness in reducing the exclusion of children with ASD in SA. During the period of this study, a review of the Disability Standards for Education was announced, making this research timely. In part the Review seeks to understand the Standards' effectiveness, due to growing concern among the disability community about whether the Standards are making their desired impact (Innes 2010). Politically, there are calls for Government action to remove barriers to accessing education, and to secure the best possible educational outcomes for students with disabilities (Pyne & Fifield 2010). The Review of Disability Standards for Education discussion paper acknowledges that although the Standards offer guidance on implementation, there is room for interpretation in application (Department of Education, Employment and Workplace Relations 2010).

Improving the current Standards, and understanding the need for increased levels of support, is only possible through hearing from those people directly affected (Innes 2010). Lack of relevant research has severely limited education providers' abilities to meet student needs and facilitate their optimum learning (Humphrey & Lewis 2008b).

The current study aims to broadly consider the effect of the Disability Standards for Education (2005) on the exclusion of children with ASD from mainstream schools.

1.5 Aims and Research Questions

The study's main aim was to examine whether the Disability Standards for Education have affected the rates of exclusion of children with ASD from mainstream schooling, by researching the perspectives of those affected through exploring qualitative responses and identifying response themes.

Research Questions:

This is a qualitative study, with three broad research questions as opposed to hypotheses. The first research question was to explore, from the perspective of families, the levels to which children with ASD in SA are being excluded from mainstream schools. A questionnaire and further in-depth interviews served to do this by garnering parents' opinions and finding out about their lived experience.

The second research question was to identify whether parents' experience has differed since the implementation of the Disability Standards for Education (2005) and determine how familiar parents are with the legislation.

The third question was to explore, from the perspective of families of children with ASD, how their experiences are in keeping with the principles of inclusive education which underpin the DDA (1992). Families were asked how familiar they are with these principles, as well as finding out about their experience in the school system.

The thesis has six chapters. Chapter Two discusses the development of the DDA and the Disability Standards for Education. Chapter Three outlines the study design and underpinning method, whilst Chapter Four details the study results. Chapter Five provides a discussion, and Chapter Six provides a conclusion of the findings, implication of results, study limitations and future research directions.

Chapter 2 – Developments in formal education for children with disabilities

The development of the Disability Discrimination Act (1992) (DDA) and its accompanying Standards for Education provided Australian schools, for the first time, with clear guidelines regarding their responsibilities towards children with disabilities. Choice, access, inclusion and integration are key concepts informing this legislation. The philosophy behind these moves towards inclusion is explored further in this chapter, as are understandings from research around 'successful' inclusion. This chapter also explores the current definition of ASD, schooling options for children with ASD in SA and summarises research findings regarding exclusions within schools both from an Australian and United Kingdom (UK) context.

There has been little research into the effects of the implementation of the Disability Standards for Education in regards to exclusion from mainstream schooling of children with ASD in SA. Despite large numbers of children with ASD now attending mainstream education placements, the facilitation of this remains a poorly understood area of education in Australia and other countries (Barnard, Prior & Potter 2000; Davis & Florian 2004; Innes 2011; Humphrey & Lewis 2008b).

2.1 The philosophy behind inclusion

Inclusion is a central idea informing the DDA and its accompanying Standards. The Centre for Studies on Inclusive Education, in the UK, states that 'inclusive education is a human right, it's good education and it makes good social sense' (cited in Department of Education and Children's Services 2007, p. 77). Inclusion in education has been identified as greatly enhancing inclusion in society; it is recognition of the right of students to access quality education in their local area and increase participation. It is also a means to reduce exclusion from local school activities and communities (Department of Education and Children's Services 2007, p. 77).

In an educational context, inclusion is also used to mean the ‘continuous process of increasing the presence, participation and achievement’ of young people in their local schools, with ‘presence’ referring to admissions, attendance and the extent of the use of exclusion from the classroom (Moore, Jackson, Fox & Ainscow 2004, p. 7). Inclusion is centred on students receiving the same quality of education and requires a ‘continuum of provisions to meet a continuum of needs’ (Hornby, Atkinson, Howard 1997 cited in Ministerial Advisory Committee: Students with Disabilities 2001b, p. 3; National People with Disabilities and Carer Council 2009). This notion of ‘same quality’ rejects the view that ‘impairment automatically means devalued social status’ (Tregaskis 2004, p. 152). It further implies that people need to be treated as individuals and given choice of a full range of options, as opposed to simplistic categorisations which do not fully recognise people’s individuality (Fullwood 1990).

‘Inclusion’ is often used synonymously with ‘integration’. The desired outcomes of integration are very similar to those outlined in the Education Standards; for people with disabilities to have the same chances and choices in life and participate in activities and be a full member of life’s communities (Fullwood 1990, p. 3; Hall 1997). Although critics seeking to dismiss the concept argue that fully embracing ‘integration’ would remove the need for special services, this is not the case, rather it highlights the need for choice to be available in a variety of settings (Fullwood 1990). This is not about eliminating particular communities, but about providing a range of choices and options which focus on a person’s abilities as opposed to their disability (Fullwood 1990). A stereotypical view of what ‘integration’ means makes it extremely hard for parents who are arguing that their child be treated on an equal basis and be integrated, but also arguing for additional resources to support their child’s needs (Riddell 1996).

The values underpinning integration as a concept resonate with social work values (Fullwood 1990). As defined in the Blackwell Encyclopaedia of Social Work (2000) the worth and uniqueness of every person is a first principle; that each person is valuable, and everyone should be treated with respect. Furthermore, that every single person or group is entitled to social justice, and everyone is entitled to their own belief systems and the freedom to do as they desire.

In contrast, segregated services and options, such as special schooling, are said by many to reinforce prevailing negative attitudes and stereotypes surrounding disability. Critics of special education argue that the history of segregated schooling is rooted in the desire to 'contain and control', a reflection of an increasingly managerial culture (Riddell 1996). Riddell commented on the increasing exclusion of students with behavioural difficulties in the UK, which he attributed to factors including school performance indicators (upon which a perceived negative impact would likely result from the inclusion of the students under discussion) and schools' perception that the inclusion of students with complex needs is 'too great a burden and liability' (Riddell 1996, p. 101). Leading up to the implementation of the DDA and the Standards in August 2005, many parents were increasingly worried about the social isolation experienced as a result of segregation, with the view that 'children will only grow and learn optimally in ordinary classrooms amongst their typical neighbourhood peers' (Hall 1997, p. 7).

Critics of these options call for increased choice and integrated approaches (National People with Disabilities and Carer Council 2009; Riddell 1996). Supporters of integrated approaches believe that mainstream settings can adequately meet individual needs, while at the same time provide benefits for both people with disabilities as well as the broader community, negating the consequences of segregation for a child outside school (Fullwood 1990; Hall 1997). Hall described the practice of compulsory segregation on the basis of perceived impairment as an 'injustice' (Hall 1997, p. 1).

An inclusion agenda is evident in the DECS 2009 attendance policy, which highlights the importance of maximising school attendance, to ensure the best possible life outcomes for a person. Disrupted attendance patterns, such as non-attendance or irregular attendance, can be indicators of future disengagement, which has a detrimental effect on the individual's capacity to acquire basic skills to ensure active citizenship and maintain relationships (Department of Education and Children's Services 2009). It also has economic implications when considering the ideological perspective that education is a basic need that everyone has a right to access, which has the potential to break cycles of inherited disadvantage and spawn other benefits such as economic efficiency and increased employment (Dalton et al. 1996). The findings of the report conducted for the National Children's and Youth Law Centre (Flynn 1997) were that equal access to education is crucial for providing equal opportunities for employment, having long term economic implications as social welfare dependence is reduced.

Inclusion policies are however not only valuable on an economic level; they are also valuable on a humane level (Flynn 1997; National People with Disabilities and Carer Council 2009). Inclusion policies allow children with disabilities a range of personal benefits on the same level that education can provide for children without disabilities, including self esteem, sense of identity, emotional, social and personal development and networks (Flynn 1997; Ministerial Advisory Committee: Students with Disabilities 2001a; National People with Disabilities and Carer Council 2009). Integrative approaches also provide increased chances and choices and provide functional learning opportunities, while simultaneously creating increased awareness in the community regarding abilities (Fullwood 1990). The benefits resulting from active participation in schools are significant in regards to lasting influence (Flynn 1997).

2.2 Research on conditions for successful inclusion

There is a small body of work on the preconditions and factors for successful inclusion. These include case management, as well as specialised support for those students who experience repeated suspensions resulting in prolonged absences from school (Ministerial Advisory Committee: Students with Disabilities 2001b, p. 14). Early intervention to address behaviour management issues is also deemed important, as it can be quite late when specialists and advocates are called into school situations to address these issues, when school community desire to retain the student's enrolment has been eroded (Ministerial Advisory Committee: Students with Disabilities 2001b). Early intervention in poor attendance has also been shown to improve learning outcomes (Department of Education and Children Services 2009). This can take the form of continual monitoring of the situation, which is substantially different to crisis management (Ministerial Advisory Committee: Students with Disabilities 2001b).

A report conducted for the National Children's and Youth Law Centre recommended that schools ensure students with disabilities are included in all aspects of the school program, that every school has copies of and are familiar with anti-discrimination legislation, and that constructive and open complaints processes be implemented (Flynn 1997). Situation specific and flexible approaches have been shown to be the most successful practices for integration, as they recognise the varied support needs of students (Ministerial Advisory Committee: Students with Disabilities 2000 cited in Ministerial Advisory Committee: Students with Disabilities 2006). The label or diagnosis a student presents with should never determine what supports and curriculum are put in place – they need to be structured around the student's individual abilities and characteristics (Kluth 2003; Ministerial Advisory Committee: Students with Disabilities 2010).

Given the focus of this thesis on educational experiences for students with ASD, I now turn to overview the condition called Autism Spectrum Disorder, and educational implications for students with ASD.

2.3 Autism Spectrum Disorders

Autism is extremely complicated and hard to define because no two people experience it or present in the same manner (Kluth 2003; Ministerial Advisory Committee: Students with Disabilities 2010). However, as Humphrey writes, 'all individuals on the autism spectrum share a common difficulty in making sense of the world' (Humphrey 2008, p. 41). Autism was first diagnosed in the 1940s by an American psychiatrist and is one of the most common developmental disorders (Kluth 2003, p. 4).

The *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition-Text Revision (DSM-IV-TR*) states that for a diagnosis of autism to be applied, an individual needs to be observed to have delayed or abnormal functioning in at least one of three areas; social interaction, communication and patterns of behaviour (APA 2000 cited in Kluth 2003, p. 5; Ministerial Advisory Committee: Students with Disabilities 2010).

'Autism spectrum' is an 'inclusive term used to encompass a range of neurologically based pervasive development disorders', which is made up of five disorders:

- Autism
- Asperger Syndrome
- Pervasive developmental disorder not otherwise specified (PDD-NOS, or atypical autism)
- Rett Syndrome
- Childhood disintegrative disorder (Autism SA cited in Ministerial Advisory Committee: Students with Disabilities 2006, pp. 9-11).

In SA, 'Autism Spectrum Disorder' is taken to mean only autism and Asperger Syndrome, meaning services operating with State Government funding, such as education sectors and services of Autism SA, do not extend to those with a diagnosis of PDD-NOS (Ministerial Advisory

Committee: Students with Disabilities 2010). It has been suggested that the DSM V (due to be published in 2013) is considering merging the currently separate categories into one category of Autism Spectrum, as opposed to autism, Asperger Syndrome and PDD-NOS (Ministerial Advisory Committee: Students with Disabilities 2010).

Seventy per cent or more of children with autism also have an intellectual disability (Brigg 2009), however a diagnosis of Asperger Syndrome or high functioning autism precludes this diagnosis. Students with Asperger Syndrome who often have very difficult behaviours are generally not placed in special schools, or special classes or units within their local schools, because they do not have an intellectual disability (Ministerial Advisory Committee: Students with Disabilities 2001b, p. 12). Students who are towards the high functioning end of the spectrum, such as those with Asperger Syndrome, are often more susceptible to emotional stress because of their ‘ability to recognise their own (social and communicatory) differences but their *in*ability to identify the cause of such differences or how to compensate for them’ (Connor 2006, para. 4). Research shows that children with ASD present with a range of different learning needs, and no one style of provision will be able to meet the needs of all students with ASD (Ministerial Advisory Committee: Students with Disabilities 2010).

Approximately 11 per 1000 (1:90) children between the ages of six to twelve years have ASD (Buckley and Martin cited in Ministerial Advisory Committee: Students with Disabilities 2010), and research suggests that the prevalence of ASD is 6 per 1000 people (1:167) (Australian Advisory Board on Autism Spectrum Disorders 2010; Autism SA 2009). Four times as many males as females are diagnosed with autism, and ten times as many males as females are diagnosed with Asperger Syndrome (Autism SA 2010a).

2.4 Learning options for students with Autism Spectrum Disorders in South Australia

Given the high prevalence of autism in children and the diversity in the way it presents, a variety of learning options are available in SA[3].

These include:

- Disability support programs: Support provided to work alongside others in mainstream settings
- Special classes: Setting for students with disabilities who need extensive curriculum support
- Special units: Long-term educational options in local schools for students with significant/multiple disabilities
- State-wide Transition Centres (located at Daws Road and Prospect): Employment based programs to assist students transition to post school options for students enrolled in DECS schools

(Department of Education and Children's Services 2007, p. 10).

The three education sectors in SA of Government, Catholic and Independent all provide services for students with ASD. For students with Asperger Syndrome, there were three alternative settings in SA, however only a small number of students experiencing significant problems in their local schools access these options (Ministerial Advisory Committee: Students with Disabilities 2006, p. 3). There was a specialist class for a maximum of eight students with Asperger Syndrome at Kensington Centre (which is a State special school), but this closed in 2009 when enrolment numbers reduced (Ministerial Advisory Committee: Students with Disabilities 2010), leaving the two remaining alternative settings as Open Access College or home schooling

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[3] It is lawful to provide special learning programs because the DDA legislates for the possibility of providing special measures, however no person can be forced to take part in special measures.

(Shearer, Butcher & Pearce 2006). A report conducted by MAC:SD into students with disabilities and complex needs identified limited capacity within special units and classes for those students who meet the criteria to be placed in these settings (Ministerial Advisory Committee: Students with Disabilities 2001b, p. 12). There are no ASD specific schools in SA as there are in New South Wales and Victoria, but these are currently being planned by the State Government, including new satellite schools (Ministerial Advisory Committee: Students with Disabilities 2006; Ministerial Advisory Committee: Students with Disabilities 2010). In South Australia, support services for students with a disability to ensure access to full participation in educational activities include Disability Co-ordinators, Psychologists – Education Services (Early Childhood) and Guidance Co-ordinators (Australian Government 2010).

If a principal believes that a child would be best suited to a non-mainstream schooling option but the parent disagrees, the parent has the legal right to reject this and enrol their child in the local school (Department of Education and Children's Services 2007). Recent submissions to studies conducted in Australia have indicated that the current lack of inclusion within the system is forcing parents to choose specialist options, even when they would prefer their child to attend their local school (Hall 1997; National People with Disabilities and Carer Council 2009). Results of a survey conducted by MAC:SD indicated that parents prefer a range of schooling options for their children, with different individuals preferring different settings but all parents valuing the ability to choose (Ministerial Advisory Committee: Students with Disabilities 2001a).

2.5 Practices of exclusion from schools

The National Disability Strategy Consultation Report 2009 identified exclusion as a critical issue, with people with disabilities being excluded, segregated, marginalised and ignored on a daily basis, with more than 29 per cent of respondents identifying the education system as a current barrier to achievement and independence (National People with Disabilities and Carer Council 2009). Students on the autism spectrum, particularly those with Asperger Syndrome, have ‘increasingly presented significant support and service challenges, as evidenced by a high number of suspensions and exclusions’ (Ministerial Advisory Committee: Students with Disabilities 2006, p. 1). Other problems identified include a limited capacity to meet the needs of students with disabilities, the benefits of inclusion are not promoted and teachers have minimal training around disability which further perpetuates ignorance and fear (National People with Disabilities and Carer Council 2009, p. 6).

The issue of suspension is a significant issue for students with a disability (Ministerial Advisory Committee: Students with Disabilities 2001b). An example is children who are excluded after attending schools for a period, with reasons cited such as that their behavioural problems ‘didn’t suit the environment’, despite the school having been fully informed before the child commenced (National People with Disabilities and Carer Council 2009). Moreover, research conducted by the Department for Children, Schools and Families in the UK demonstrated that exclusions of more than one or two days can cause problems for the child reintegrating into school (cited in National Autistic Society 2010). This is further compounded by the fact that for students with a disability who are ineligible for special settings (such as students with Asperger Syndrome), mainstream schooling is their only option (Ministerial Advisory Committee: Students with Disabilities 2001b). Exclusions can severely limit the opportunities for students with ASD to receive an education.

Exclusion can occur both formally and informally. Students who experience an ongoing reduction in the lessons that they are allowed to attend (such as students who are allowed conditional re-entry after facing suspension) are potentially facing indirect discrimination, as the needs of the student are what must be taken into account (Department of Education and Children's Services 2007). This discrimination can happen indirectly, such as the situation of a boy with Asperger Syndrome who is at home with his mother full-time after being expelled from his local school, and the family cannot find another school to take him (National People with Disabilities and Carer Council 2009). Hundreds of children with ASD across the state are attending school for limited amounts of time, or not at all, with exclusions and suspensions common (Clarkson 2009).

An example of the kind of discrimination a child with autism may face in regards to exclusion is found in the DECS 2007 Report. The Report recounts the situation of a ten year-old child who had never attended school full-time. His parents initially faced refusal by the school to accept the child and then resistance in the form of failure to provide alternative educational programs for the boy (2007, pp. 9-13). This discrimination is at odds with the Disability Standards for Education (2005) which state that 'if the parents do not wish to have their child in a specialised setting, site and agency support personnel must develop the required support structures and processes to maximise the likelihood of positive educational outcomes for learners' (Department of Education and Children's Services 2007, p. 33). Recent research reported by Briggs indicates that despite the Standards, educators in mainstream schools are struggling with responding to the needs of children with ASD and challenging behaviours (Briggs 2009).

Furthermore, exclusion of a student (via suspension or expulsion) who is unable to understand a school's behavioural policy, or whose understanding is impacted by their disability, is an example of indirect discrimination (Department of Education and Children's Services 2007).

An example reported by the Human Rights and Equal Opportunity Commission of a mother whose son has ASD, details how he was suspended from school when he stood up to bullies (cited in Department of Education and Children's Services 2007). The mother argues discrimination had taken place as the bullies had not been reprimanded (Department of Education and Children's Services 2007, p. 71).

Research conducted in the UK indicates that 21 percent of children with ASD are excluded from school at least once, significantly higher than children with other disabilities and 20 times higher than those without special education needs (Barnard, Prior & Potter 2000; Humphrey & Lewis 2008a). Humphrey and Lewis' in depth qualitative study in four secondary schools in England focussed on the views and experiences of 20 students with ASD, in response to calls for more research in this area, as well as to examine the effectiveness of inclusive education for students with ASD (Humphrey & Lewis 2008a; Humphrey & Lewis 2008b). Their method involved conducting semi-structured interviews with the students themselves, student diaries detailing their experience, student drawings, plus interviews with education and service providers and parents (Humphrey & Lewis 2008b).

Humphrey and Lewis' study found that a number of barriers can exist to students with ASD gaining the full benefits of inclusive education. Furthermore, how 'inclusion' was understood was critical in determining the level to which government policy was implemented. They observed that 'the gap between 'inclusion rhetoric' and 'classroom reality' was very wide in some schools' (Humphrey & Lewis 2008b, p. 138). For participants in the study, the diverse characteristics of students with ASD provided both challenges and opportunities within mainstream settings; issues of bullying compounded increased levels of social isolation for many participants, whilst a select few found that the positive relationships held with their peers had more of an effect on the success of inclusion than the influence of the teacher (Humphrey & Lewis 2008a, p. 37). Humphrey and Lewis (2008) concluded that a lack of research in this area means that education providers are often unprepared and unable to meet the range of needs that a student with ASD might present with. They suggested a clear need for more research across different settings to account for the broader population of students with ASD (Humphrey & Lewis 2008a, p. 42-43).

The National People with Disabilities and Carer Council has also contributed to understandings in this area. As part of a process informing development of a National Disability Strategy, they conducted a national consultation called ‘Shut Out: The Experience of People with Disabilities and their Families in Australia’ (Australian Government 2010). It found that exclusion of children with disabilities within the education system is both systematic and systemic (National People with Disabilities and Carer Council 2009). Despite the legislation detailed above and Education Standards introduced in 2005, the system is still not responding to the needs of students with disabilities (National People with Disabilities and Carer Council 2009).

Research in the UK shows that a considerable number of children with ASD face exclusion from their schools (National Autistic Society 2010), despite the vast changes in and development of inclusive educational policy in the past decade, similar to the DDA and its accompanying Standards in Australia (Humphrey & Lewis 2008b). However, akin to the current situation in Australia, there is limited research around the actual effects of relevant policy in schools, or whether these policies are being fully implemented (Humphrey & Lewis 2008b). Despite increasing numbers of students being educated in mainstream settings, the ‘limited research in this area has indicated that their experience of school is often marked by bullying, social isolation and anxiety’ (Humphrey & Lewis 2008b, p. 132).

The National Autistic Society in the UK conducted a survey of parents in 2000, which consisted of a questionnaire that was sent out to their 2409 members across the UK (Barnard, Prior & Potter 2000). They received over 1100 responses, but only analysed the first 1000. The questionnaire was divided into three sections, the first for completion by parents or carers of school aged children, the second for parents or carers of adult children, and the third for people who had ASD. The study was focussing on inclusion, and looking at respondents' satisfaction with different education settings, and educational opportunities in general. The lowest level of satisfaction indicated by parents was with mainstream settings in which support was described as non-existent or very limited, and high levels of satisfaction were related to the early years of education, declining as children reached later school years (cited in Connor 2006).

2.6 Review of the Disability Standards for Education

On the 1st of December 2010, Graeme Innes, the Disability Discrimination Commissioner, made a speech in Brisbane where he admitted that the Disability Commission 'do not know anywhere near adequately where we are at' in terms of eliminating discrimination, and that they do not know 'what level of success the DDA and equivalent State and Territory legislation is having in promoting systemic change and achieving equality of opportunity in education' (Innes 2010, para. 6).

During the writing of this thesis, the Australian Government announced a Review of the Disability Standards for Education and released a discussion paper on the 15th of February 2011 (Garrett & McLucas 2011)[4]. The primary aim of the Review is to determine whether the Standards are effective, and if they are the most appropriate way of achieving the objectives of the DDA (Department of Education, Employment and Workplace Relations 2010; Garrett & McLucas 2011). The discussion paper states that the Review will consider whether the Standards have achieved their aim of making responsibilities under the DDA easier to understand, have assisted people with disabilities to participate in education, have helped to eliminate discrimination and have promoted acceptance in the community around rights and disability (Department of Education,

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[4] The Standards outline a requirement for a review to be completed no later than five years after their implementation; however this was reportedly delayed due to the Federal election (Innes 2010).

Employment and Workplace Relations 2010, p. 7). Face to face interviews will take place in capital cities as part of the review process, as well as ‘broader consultations’ with appropriate disability organisations (Garret & McLucas 2011). The Review primarily seeks to determine whether the Standards are ‘the most effective mechanism they can be for achieving equal opportunity in education for people with disability’ (Innes 2010).

In conclusion, a reading of the literature shows that investigating the mainstream schooling of children with ASD is a complex area, and one which requires further research. Inclusion and integration are important values, which are based on human rights. Research shows preconditions and factors that support inclusion are specialised support, early intervention and flexible approaches structured around student needs. This however requires resources, attention to discrimination, addressing bullying and maximising peer supports. The design of the study is outlined in the following chapter.

Chapter 3 – Method

The focus of this chapter is the method used in this research about the effects of the Disability Standards for Education on the inclusion and exclusion of children with ASD in mainstream schooling. Outlined below is the study design, participant recruitment and the research process. The research addresses three research questions: to explore, from the perspective of families, the levels to which children with ASD in SA are being excluded from mainstream schools; to identify whether parents' experience has differed since the implementation of the Disability Standards for Education (2005) and determine how familiar parents are with the legislation; and to explore, from the perspective of families of children with ASD, how their experiences are in keeping with the principles of inclusive education which underpin the DDA (1992).

3.1 Study design

The study was a mixed methods study with the aim to concurrently collect and embed quantitative data within the context of a larger body of qualitative data (Creswell 2009). Qualitative approaches are appropriate when the researcher is interested in people's reactions, interpretations and opinions – an interpretive approach leading to subjective findings (Denzin & Lincoln 2001). This comes from a phenomenological perspective, which places importance on subjective reflections and the view that 'the 'reality' of a given educational setting may not be seen as a fixed and stable entity', but instead as something that can only be perceived via an analysis of these reflections (Burns 2000, p. 11).

Qualitative approaches, as the SA Community Health Research Unit state, allows the researcher to 'derive information not only from what people tell us, but also from our observation of what happens', allowing for greater understanding and perspectives of social problems (SA

Community Health Research Unit 1991, pp. 22-23). While qualitative research is sometimes criticised by some for not producing data that can be expressed statistically, the current method incorporates quantitative information within a qualitative study to add to the researcher's ability to answer the questions posed above (Mayring 2000; SA Community Health Research Unit 1991).

The study design involved administering a survey (details of which are discussed below) to obtain general information about the participants' children, schooling and their experiences. Some of the information provided was able to be reported in a quantitative manner, however the sample size was not large. The survey also provided participants with the opportunity to add open comments regarding their experiences and interpretations. The qualitative method of semi-structured interviews was then conducted with some of the survey respondents which enabled the research questions to be explored in depth.

3.2 Ethical considerations

Ethical considerations for this study were reviewed by the Social and Behavioural Research Ethics Committee from the Flinders University of South Australia. Permission for undertaking this research was granted by the Committee prior to commencement of the study.

Autism SA required the study to gain approval from their Professional Practice Committee prior to being advertised to registered families in their monthly newsletter. The Autism SA Committee requested several changes, including return date, wording in the letter of introduction and the list of agencies to contact if participants were adversely affected by taking part in the research. The Social and Behavioural Research Ethics Committee approved the modifications before the amended questionnaire was circulated.

3.3 Recruitment

Relevant agencies, as identified by researching current services in SA in contact with parents of children with ASD, were contacted via email and sent a letter of introduction from Associate Professor Fiona Verity on behalf of the Social Work Discipline (Appendix A). The agencies that were contacted were Autism SA, Community Living Project, Disability Information and Resource Centre, Family Advocacy, Julia Farr Association, Relationships Australia, South Australian Council of Intellectual Disability and the South Australian Council of Social Services. A copy of the questionnaire used in the study, which contained a summary of the purpose of the research and participation requirements such as level of commitment, along with provisions made for privacy and other information, was also attached (Appendix B). Agencies were asked to indicate via return email whether they gave permission to be involved in the study by passing the letter of introduction on to relevant families. The letter of introduction then invited those interested to contact the researcher via email.

Interested families sent the researcher an email requesting more information about the study, during which time the researcher answered specific queries and provided any information that was requested. The email replies from the researcher gave the letter of introduction, questionnaire and a consent form for participants who agreed to be involved in the follow up interview (Appendix C). Written consent was obtained from all those who participated in the follow up interview. Snowball sampling occurred when interested agencies or individuals contacted the researcher who were not able to participate, but were asked to pass the details of the study onto appropriate members of the community (Burns 2000).

3.4 Inclusion and exclusion criteria

To be considered eligible for the study, participants had to be parents who have, or have had, a child with ASD at a mainstream school in SA, regardless of the length of time the mainstream school was attended, or whether that child had experienced exclusion.

Eleven service providers responded to the request for participants, including five from South Australia, two from New South Wales and four from Queensland. These included two teachers, three government workers and six service providers from non-government organisations. These respondents were not eligible to participate in the study as they were not parents of children with ASD, however those within SA who worked for a relevant agency were asked if they were willing for their agency to be involved in the study. Two agencies who had indicated interest in participating sent out the information. Service providers who were interstate were thanked for their interest. One member of the National Disability and Carer Council contacted the researcher for further information to report to senior members of the Department of Education, Employment and Workplace Relations at a preliminary meeting for the review of the Disability Standards for Education.

Three other people contacted the researcher who did not fit the inclusion criteria, as two were parents from interstate and one was a grandparent whose child was in a specialist setting.

3.5 Materials

Questionnaire

Participants were asked to complete a six-page questionnaire with a total of 28 questions using yes/no answers, ranking experiences in check boxes and open-ended responses (Appendix B). Questions were based around key themes informed by the relevant previous studies discussed in Chapter Two.

The four sections of the questionnaire were:

1. *About your child*

   Participants were asked for details about their child's age, diagnosis, schooling and support.

2. *Your involvement with your child's schooling*

   Participants were asked about the level of choice and involvement they had in their child's schooling, as well as questions about any exclusions and their effect on the child and their family.

3. *Your child's experience of inclusive schooling*

   Participants were asked to share their perception of inclusive education, as well as their child's experiences of inclusion and support within the school.

4. *Your understanding of school policies*

   Participants were asked about their understanding of school policies, as well as their views on how effective these are in practice.

Interviews

Semi-structured interviews were focused around a list of topics relating to the central thesis questions, without fixed wording or sequence which allows the researcher to delve further in to participants' experiences than would be possible using a more rigid survey style interview (Minichiello, Aroni & Hays 2008, p. 51). Appendix D summarises the range of questions asked during interviews. Participants were given the opportunity to add additional comments at the end of each interview and the interviewer was at liberty to ask additional relevant questions.

Data were recorded during the interviews using a tape recording device, to avoid interrupting the flow of interviews through taking excessive notes (Liamputtong 2009).

3.6 Procedure

Participants were asked to indicate their willingness to be involved further in a follow-up interview when they returned their questionnaire, along with their consent form. Interviews were intended to be conducted in person at Flinders University, or at the participants' home if they were unable to travel, however, as several of the participants lived rurally, interviews were conducted over the telephone. Seven interviews were conducted.

3.7 Analysis and reporting of results

All information obtained was treated as confidential. Participants were telephoned and responded to by name, but in reporting and calibration of results, only de-identified data was used. Quantitative data were analysed using PASW Statistics 18 (SPSS, Inc., Chicago, IL).

Liamputtong (2009) deems thematic analysis to be more appropriate for use in qualitative data analysis than other forms of analysis, such as content analysis, which is better suited to quantitative studies. The information for this study was therefore coded to determine themes within the material gathered. Themes were structured around themes emerging from the literature review, along with common themes within participant responses.

3.8 Participants

Twenty one surveys were completed and 7 interviews took place. Of the 21 participants who returned completed surveys, 19 indicated interest in participating in a follow-up interview, but only 7 provided the appropriate information and consent forms for these to take place.

3.9 Non participants

While 33 people indicated interest in participation via email or telephone, 12 people did not return surveys or respond to further emails. Two people expressed interest after the study had closed. Of those who returned surveys, 19 indicated that they would be interested in participating in a follow-up interview. Of those who indicated willingness to participate in the interviews, 12 returned signed consent forms but only 7 replied with an appropriate time for the interview to be conducted and contactable phone number. Of the 12 who returned consent forms, 3 provided consent forms after the survey was closed. Two additional participants returned electronic consent forms with no signature attached.

One participant had trouble with the format of the questionnaire due to their inability to currently use their hand, causing problems with completing it electronically and they were not able to complete a hard copy. Unfortunately, because they became involved late in the research period, an alternative method of participation was not identified before the study was required to be completed. One participant indicated ‘no’ to participating in a follow up interview, and explained that it was due to restrictions put on her in her negotiations with authorities to speak publicly about her schooling experience.

In conclusion, a mixed methods design was utilised to address the three research questions. A questionnaire was administered and follow up interviews conducted, with 21 parents of children with ASD participating. The data collected through these methods are outlined in Chapter Four.

Chapter 4 – Results

The reporting of results is covered over the next two chapters. The results from the survey are primarily the focus of this chapter, whilst Chapter Five draws further on comments from the interviews. A discussion of these results in relation to the research questions is also the focus of Chapter Five.

4.1 Descriptive responses

As indicated in the previous chapter, 21 survey responses were received. Descriptive information gathered about the children is reported below.

4.1.a Age of children:

Eleven participants had children between the ages of 5-11, 8 had children between the ages of 11-15 and 2 had children aged 16 and over. Five participants indicated that they live in a rural area, and 2 indicated that their child is schooled privately, despite these questions not being included in the questionnaire.

4.1.b Current school setting:

Table One shows the breakdown of current school settings attended by the children referred to in the study, with 52.4 per cent of children attending mainstream schools, defined as a non-specialist setting. The second largest group are children in a special class at a mainstream school (28.6 per cent).

Table 1. Schooling setting of participants' children

	Frequency	Percent (%)
Mainstream school	11	52.4
Special class at mainstream	6	28.6
Special school	2	9.5
Left school	1	4.8
Home schooled	1	4.8
TOTAL	21	100

4.1.c Diagnosis of Autism Spectrum Disorder:

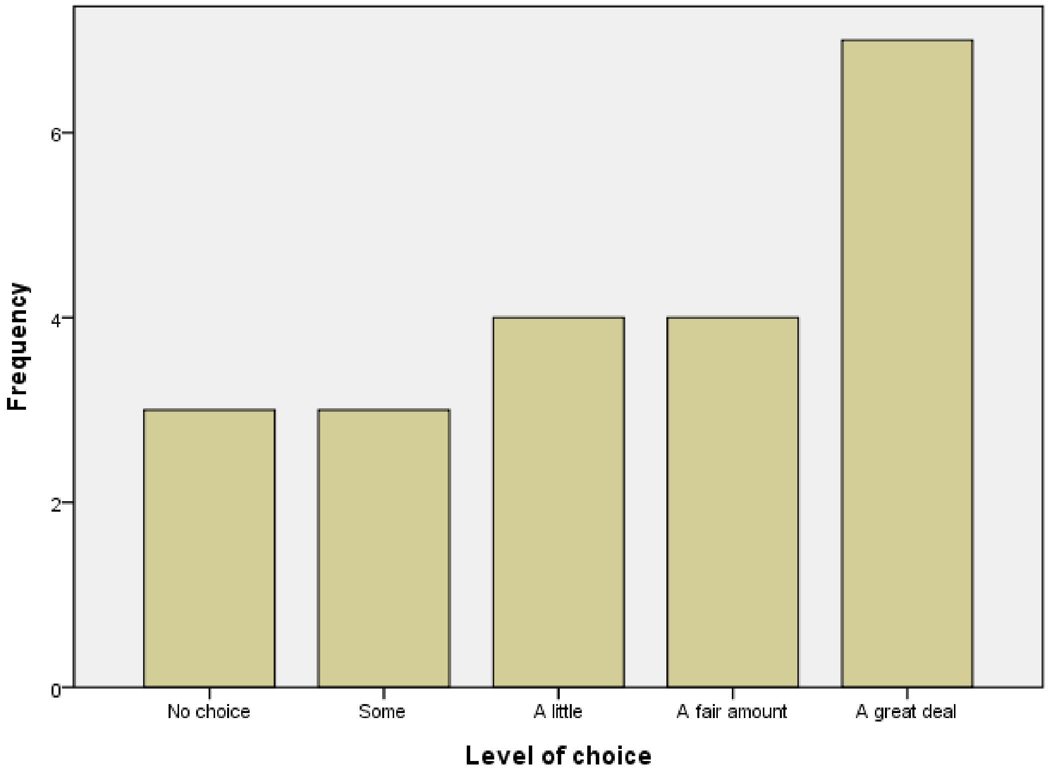
Of the 21 participants, 17 had children with a diagnosis of Asperger Syndrome, and 5 indicated that their child had a diagnosis of an intellectual disability as well as ASD. This number is incongruent with the understanding that a diagnosis of Asperger Syndrome precludes the presence of an intellectual disability (Briggs 2009), a matter taken up in Chapter Five.

4.2 Child's schooling

4.2.a Choice:

The level of choice participants felt that they had in their child's schooling was positively skewed, as shown in Figure One. Seven participants (33.3 per cent) answered that they had a great deal of choice, 4 participants (19 per cent) stated that they had a fair amount of choice, another 4 stated they had a little choice and 3 participants (14.3 per cent) stated that they had no choice.

Figure 1: Level of choice in child's schooling



4.2.b Experience of exclusion:

Thirteen participants (62 percent) identified that their child had been excluded from school at some stage, with 5 students experiencing informal exclusion, 6 experiencing formal exclusion and 2 experiencing both types of exclusion.

As respondents reported, exclusion had resulted in increased levels of anxiety for the child, stress for the whole family and financial hardship. More specifically, 6 participants reported emotional problems such as anxiety, depression, low self-esteem and self-harm increased for their child as a result of exclusion, and 2 reported increased behavioural problems. Nine participants outlined the adverse impact on their family due to one or both parents needing to take time off from their employment in order to be able to be at home with the child during their exclusion period. As well, 6 participants indicated they became stressed, very upset or even depressed. One participant reported a marriage breakdown as a result of the stress imposed in this period. Two participants reported that their children actually enjoyed the informal exclusions, as they involved doing work in a different setting with one-on-one support.

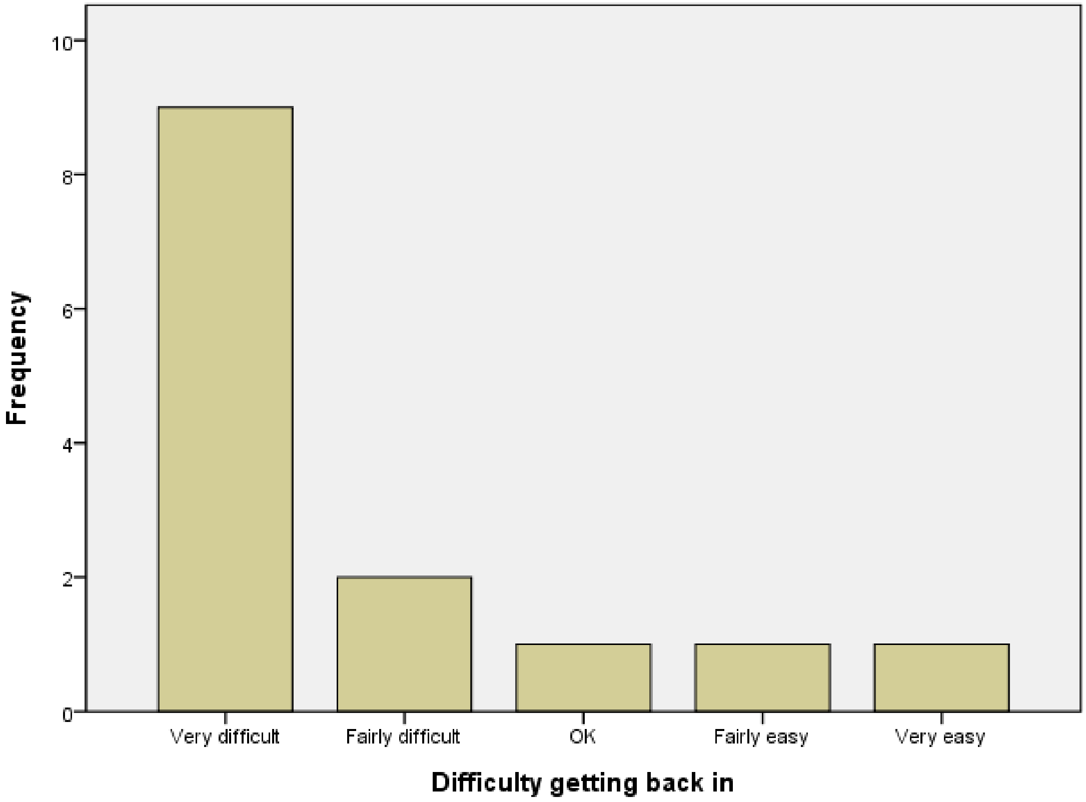
These exclusions ranged from one day of exclusion, to 12 months exclusion, to parents being asked to permanently remove their child from the school. The children of 3 participants are still not allowed to attend school fulltime. Other experiences of exclusion include a participant being requested to withdraw their 5 year-old son from enrolment; a participant being asked not to bring their child to school on certain occasions; one participant voluntarily withdrawing their child before the exclusion officially took place and in one case a student was assaulted by a teacher. Three participants expressed that the exclusion(s) they experienced would have been preventable if adequate supervision was in place, or if other students were more understanding of ASD. As to the contributing factors, 4 participants reported exclusions occurring as a consequence of their child being a victim of bullying, and resultant behavioural responses of their child. Five participants recounted times when the school had called them to pick their child up early, due to reasons such as difficulty controlling emotions, 'tiredness' or poor behaviour.

4.3 Issues around re-accessing education following exclusion

4.3.a Re-entering:

Of those whose child had been excluded at some stage, 9 participants (64.3 percent) answered that they found it very difficult for their child to re enter schooling (shown in Figure Two). Three participants had to get senior staff within the Education Department involved to get their child back in their school, 2 enrolled their child in a special school after the exclusion and 2 reported that as a result their child still refuses to go to school on occasion. The participant who answered that it had been 'very easy' attributed this to the school's effective use of re-entry meetings ensuring an easy transition back in to schooling.

Figure 2: Level of difficulty for child to re-enter schooling post exclusion



4.3.b Views on their child's experience of inclusive schooling:

Figure Three shows responses to a question regarding the effectiveness of the policy of inclusion, with 9 participants (42.9 percent) stating it was only 'partly effective'. They attributed this to a need for adequate and ongoing support, good intentions by the school but a lack of resources and knowledge and not enough support for both students and staff. Two participants commented that the level of support available '*depends how aggressively you attack the Department'*, whilst one participant commented that it had been very effective for their child because they had '*fought the whole way'*. Another reported a very positive experience, with their school being very supportive and inclusive. Five participants referenced the difference that individual teachers made to how effective inclusion was in practice, and stated that this also depends on the school. Seven participants commented that this, in part, was due to the extent to which teachers are committed to the principles of inclusive education. Two participants reported that they were unable to answer the question about how committed they felt teachers were to the philosophy of inclusion due to the large level of variance between each teacher (shown in Figure Four).

One person in particular reported that she had had a very positive experience so far in her child's schooling, apart from one term when her child had a relief teacher. As reported by the parent, this relief teacher served to undermine both the child's performance at school, along with her relationships with other children, and the attitude of other parents towards the child and her family. Two participants commented on the competing interests present in the classroom for the teacher, which can lead to a lack of focus on ASD.

Figure 3: Experience of effectiveness of inclusion in practice

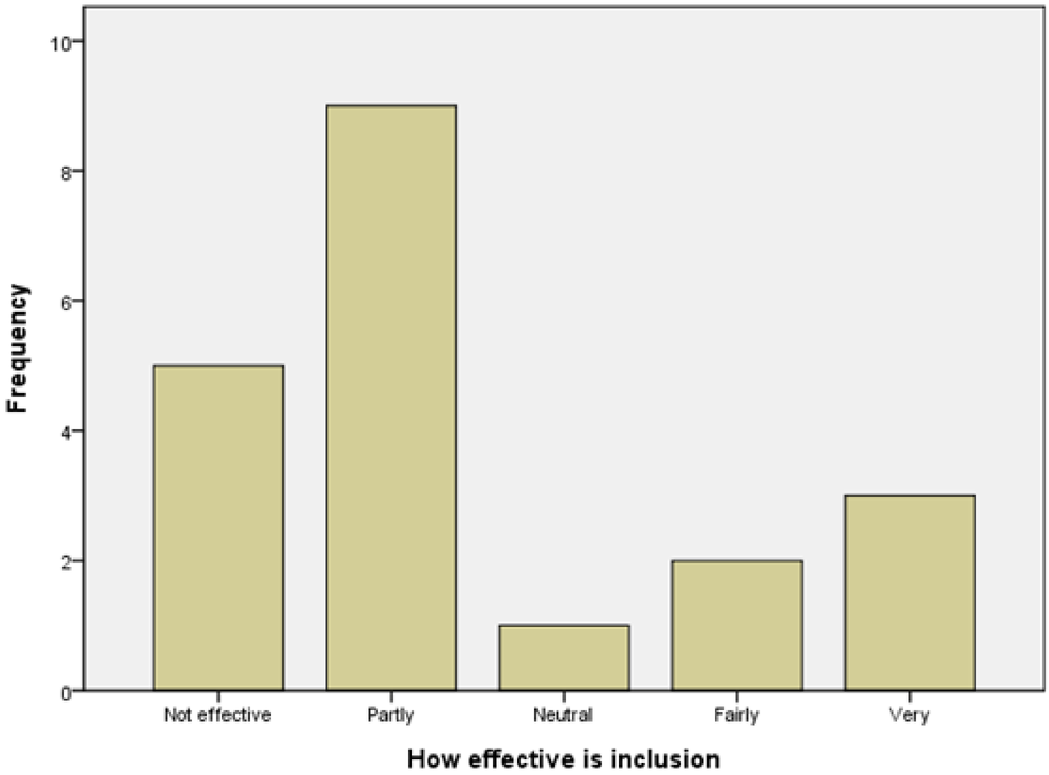
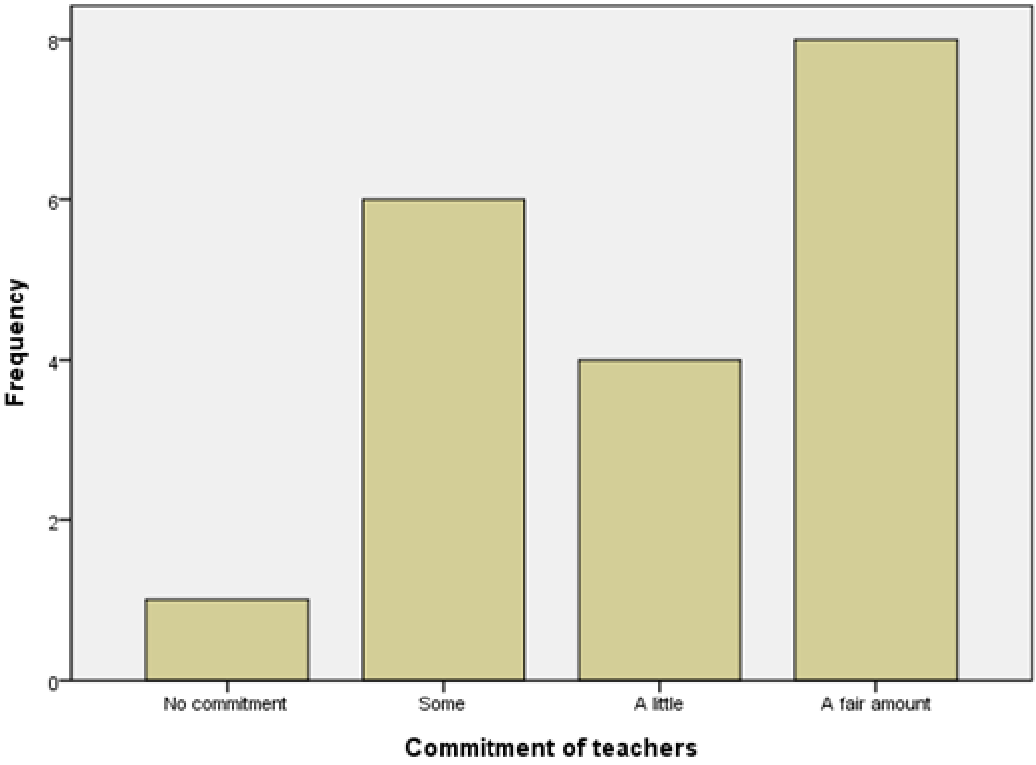


Figure 4: Experience of commitment of teachers to the philosophy of inclusion



4.4. Issues affecting child's access to schooling

Seventeen participants' children (81 percent) faced issues with access to education. As listed in Table Two, by far the most common barriers listed (by 11 participants) were social and emotional issues such as those related to sensory issues, reportedly leading in some cases to behavioural outbursts. Other issues listed (not included in the table) were regular exclusions, insufficient support hours and inadequate safety facilities.

Table 2. Issues that affected child's access to education

	Frequency	Percent (%)
Social and emotional issues	11	44
Exclusion from activities such as concerts/sports/excursions	4	16
Bullying	3	12
Comprehension/communication	3	12
Extreme anxiety	2	8
Lack of teacher understanding of ASD	2	8
TOTAL	25	100

Suggestions from participants as to how the above listed barriers to inclusion could have been addressed are listed in Table Three. Most commonly they were to do with education and responses of the teaching staff, but also were in regards to practical strategies the school could implement, such as lower class numbers, and sensory breaks.

Table 3. Suggestions as to how barriers to inclusion could have been addressed

	Frequency	Percent (%)
Education of teachers	7	33
Consistent responses of staff	5	24
Provision of a mentor/modelled behaviour program	3	14
Lower class numbers	2	9.5
Provision of strategies to assist (such as sensory breaks)	2	9.5
Adequate support hours	1	5
Promoting inclusion and adaptability	1	5
TOTAL	21	100

Twelve participants listed education of all teachers around ASD as a means to support children with ASD to feel more included within mainstream schooling. Seven called for increased resources, greater levels of support and funding according to the need of the child, not their category. Six listed education of other children as a priority, and 4 listed community education as important. Four highlighted the need for smaller classes and 3 suggested individual programs specifically for the individual child's needs be implemented.

4.5 Understanding of school policies

Fifteen participants (71 percent) were aware of policies within their child's school. Of those who responded to the second part of the question, 7 participants believed that their school upholds these policies, 7 did not think they were upheld and 2 participants were unsure. Responses were very varied, ranging from '*the school does its best in an unsupportive environment*', *'great policies but not upheld'*, 1 participant making complaints but never seeing any policies developed and 2 participants stating that policies are sometimes upheld more than others. Four respondents were not aware of school policies, and 2 were unsure.

Thirteen participants were aware of policies that apply to all schools, 5 not aware and 3 were unsure. Three participants indicated that they thought these policies were effective while a clear majority of 13 participants (61.9 percent) believed they were not effective (see Table Four). The participants who answered 'no' to this question stated that policies mean nothing without the resources to follow or the means to enforce them, implying that without a structure for implementation, they remain ineffective. Two participants stated that each school interprets them differently and 1 participant highlighted the common nature of suspensions for children with ASD as an example of them being a '*waste of time'*.

Table 4: Are the policies which apply to all schools effective?

	Frequency	Percent (%)
Yes	3	14.3
No	13	61.9
Unsure	4	19.0
Unknown	1	4.8
TOTAL	21	100

4.6 Views on the impact of the Standards for Education on inclusion

When asked whether they believed the Disability Standards for Education had had an impact on the exclusion of children with ASD, 4 participants believed they had, 12 (57.1 percent) answered that they had not and 5 were unsure. Some of the open ended comments regarding the impact of the Standards included:

- *Legislation has made teachers comply with current thinking*
- *Can’t imagine what happened to families before they were implemented*
- *The school didn’t understand the document when presented with it*
- *Parents and students are yet to be made aware of their responsibilities*
- *They are only effective if you use legal representation*
- *Most parents don’t complain because they don’t want to go to court*
- *Standards were used against child to make a complaint to HREOC on grounds of unjustifiable hardship and to exclude for nearly 12 months*

4.7 Summary of results

In the context of the research question, the survey results show that although 4 participants believed that the Disability Standards for Education had had a positive impact on exclusion of children with ASD, 62 per cent of participants have experienced exclusion from schooling, and 81 per cent of participants stated that their children had faced issues in accessing their education. Chapter Five discusses further data from the interviews that were conducted and relates the results to the literature discussed. The results from the data reported will be discussed in the following chapter, along with its implications.

Chapter 5 – Discussion

The purpose of this study was to explore, from the perspective of parents, the impact of the Standards on the exclusion of children with ASD from mainstream schooling. As shown in Chapter Four, for the parents who responded to the study, barriers continue to be faced by their children with ASD in accessing mainstream schooling, despite measures such as the Standards. Significant influences on student attendance, as identified by research conducted both in Australia and overseas, include the school organisation and climate, bullying and harassment and teaching practices (cited in Department of Education and Children's Services 2007). The results from this study are consistent with this research. The families who participated conveyed strong messages regarding necessary improvements to enable students to experience full inclusion, as well as highlighting factors which are preventing this from happening. Outlining these views is the focus of this chapter.

5.1 Overall findings of study

The predominant group taking part in this research was parents of children with Asperger Syndrome (81 percent). However, it was also noted that 7 of these children were also described by their parents as having an intellectual disability. The Autism Association of South Australia, in line with international diagnostic criteria, recognises that high functioning autism and Asperger Syndrome, although both part of the autistic spectrum, present differently. Individuals with Asperger Syndrome do not exhibit a clinically significant delay in language or in cognitive development, while either or both of these delays can be seen in people with autism (Autism SA 2010a). The time constraints of this study did not allow for determination of the accuracy of the diagnosis for each child.

The reason for the predominance of respondents with children with Asperger Syndrome could be hypothesised as potentially that this group of parents may have stronger feelings about the exclusion of their child from school, or feel that the needs of their children have received less political or educational focus than the needs of children with autism and consequently have fewer options in relation to educational settings.

The first research question was to explore, from the perspective of families, the levels to which children with ASD are being excluded from mainstream schools. Perspectives differed, and participants identified different levels of 'exclusion' in their responses. Sixty-two per cent of participants identified that their child had experienced formal or informal exclusions, but participants also identified specific activities or times in which exclusion was taking place. For example, 4 participants' children are not included in activities such as concerts and sports days, and several participants detailed that their child is excluded at lunch times. Some parents with younger children indicated that they felt that there were higher levels of support, inclusion and effectiveness of school policies, consistent with Barnard, Prior and Potter's (2000) study.

As one parent expressed, most ASD services are provided in the metropolitan area, meaning there are real limitations to the services available to students, their families and the education providers in rural areas (Ministerial Advisory Committee: Students with Disabilities 2010). Another participant spoke about these issues as follows:

> *And for [child's name], who is high functioning and has an IQ of 155, there is no choice other than mainstream schooling. No choice cos [sic] we're regional to attend another school. He is included only because they have to include him, but it is not working.*

Even with the implementation of programs such as Positive Partnerships, mentioned in Chapter One, unique barriers exist in rural areas. As one participant outlined, a five day training session was run by this program for teachers in their area, however not one teacher from their school attended. A lack of relief teachers meant it was very hard to cover teachers to go for this time, as the participant stated:

> *There is no support for the school to actually [put accommodations in place]. It's fine to say on the NEPs 'teachers will have training in such and such', well they can't have training if one, there isn't a training course being offered, or two, there isn't anyone to cover them so they can go, or pay for it.*

Teachers need adequate support and resources as students progress through mainstream classes, especially as they age and the social gap grows between students with ASD and typically developing students (Brigg 2009). Studies show many teachers are committed to the principles of inclusive education, but rarely have access to ongoing support or professional development, and believe they are restricted in their knowledge in making significant learning adjustments (Brigg 2009; Robertson, Chamberlain & Kasari 2003).

Brigg (2009) highlights the importance of effective teaching practices being grounded in extensive knowledge, empathy and understanding around the impact of ASD on the child and their behaviours. As detailed by one participant, their positive experience in education has been in large part due to the support and understanding of the school principal in working with them, even when faced with criticism from other teachers and parents. This is consistent with previous studies' findings that inclusion has to involve a commitment from everyone connected with the school (a 'top down' commitment) and that the principal is central in the effective implementation of inclusive practices (Barnard, Prior & Potter 2000; Brigg 2009; Humphrey & Lewis 2008b). As one participant stated:

> *A lot of teachers come in without understanding that, well, there's a difference between treating everyone the same, and equally, and being equitable and treating different people differently because they have different needs.*

The second research question was to identify whether parents' experiences have differed since the implementation of the Disability Standards for Education and determine how familiar participants are with legislation. Despite 13 participants being aware of policies that apply to all schools regarding disability and education, 6 participants indicated to the researcher, both in surveys and follow-up interviews, that they did not feel familiar enough with the specific Standards to comment on whether they had had an impact on levels of exclusion or not. Of participants who had children old enough to have had experience of schooling both before and after the Standards were implemented, 2 felt they were unable to comment because their children were not diagnosed until after 2005. One participant stated although she had seen a lot of changes occurring in the last seven years around awareness, that:

> *That still isn't really sort of translating to changes in how people with ASDs are included, or in fact educated. We're still having now to just try and find a way of enabling them to be educated in mainstream schools*.

Other participants argued that:

> *Policies are not worth the paper they are written on if they do not translate to action. What is needed is for good policy to be written in line with good procedures and a commitment to ensuring that all policies and procedures are followed and then regularly monitoring. But schools are so under resourced that this rarely happens.*

> *The Government can announce all the initiatives they like, but unless they actually put time and money into making sure that those legislative requirements are met, it's pretty much meaningless.*

The third research question was to explore, from the perspective of families, how their experiences were in keeping with the principles of inclusive education which underpin the DDA.

Every participant was able to define what inclusion means to them and discuss their experience of inclusion in relation to this definition. One participant defined inclusion as:

> *Three parts: inclusion as a philosophy, principles, and practices. As a philosophy, all children and families belong and are welcome in the school where diversity is valued. As an inclusive school community who values diverse learners, supports are put in place to ensure that everyone has access and can learn to the best of their ability and achieve their full potential. There is an understanding of the difference between equality and equity and the school community is committed to valuing diversity and equity in education. Inclusive practice means putting the principles of inclusion into practice. In other words, not just saying, but doing.*

The reported experience of this participant with the relief teacher who undermined her child's schooling experience is not in keeping with the definition she provided of inclusion and contravenes the requirement outlined in the Standards that 'harassment and victimisation of students with disability is unlawful and education providers must take all reasonable steps to prevent this from happening' (Department of Education, Employment and Workplace Relations 2010, p. 17). An important theme that arose throughout responses was the different interpretations, or misinterpretation, of Standards between different schools. Three participants spoke about the tendency for the Standards and other policies which apply to all schools to be interpreted in different ways. Phrases such as 'accommodation' and 'inclusion' were described as being misinterpreted or applied inconsistently. One participant commented on her son's experience of the school's perception as '*not [her] idea of 'inclusion''*; when she raised the issues of inadequate safety features for her autistic son, such as no fencing around the school which was located next to a highway, the disability coordinator suggested he could wear a fluoro vest so teachers could pick him out in the playground. Another argued that '*currently the onus is on the student and family to 'change' to fit in with the school/student body, rather than the site adapting* *to the ASD student's needs'*. This can have a detrimental effect on the student, as stated by the participant below:

> *When people are different they tend to try and sort of squash the square pegs into the round holes. And when that happens it causes enormous problems to the students who are you know, not destined to fit into those schools.*

This finding affirms the statement made in the opening section of the Review of Disability Standards discussion paper that recognises that there is room for interpretation of the Standards, and further highlights this as a real issue in the ability of the current Standards to effectively address the exclusion of children with ASD.

Whilst students with ASD are increasingly enrolled in mainstream education settings, a range of barriers limits them in making the most of their education (Humphrey & Lewis 2008a), The 2010 report of MAC:SD listed friendships, social relationships, bullying and harassment as the most difficult aspects of schooling for secondary students with ASD (Ministerial Advisory Committee: Students with Disabilities 2010). Experiences of participants are consistent with other studies which have raised concern about the distress experienced by attending school (cited in Ministerial Advisory Committee: Students with Disabilities 2010). Bullying has been identified as a major barrier, leading to non-attendance for several participants in this study, consistent with previous research (Ministerial Advisory Committee: Students with Disabilities 2001b; Ministerial Advisory Committee: Students with Disabilities 2006; Ministerial Advisory Committee: Students with Disabilities 2010).

The experiences reported by participants in regards to the barriers facing their child's schooling are congruent with research such as Brigg (2009), who details how the transition into secondary school can be a particularly harrowing time for young people with ASD as they come to terms with issues around identity and isolation, potentially leading to ongoing mental health problems. One participant discussed the psychological issues that her son with Asperger Syndrome now experiences; '*a tonne of…issues regarding self esteem, regarding social behaviours, and generally fitting in, that are now as a result of not being included or not being in a schooling system that allows him to be different'*. As this participant expressed, the experience can be overwhelmingly negative:

> *Without doubt, school is the most horrible part of my son's life to date. He has been abused by the 'system' and by many teachers, students and parents throughout the last 10 years of schooling.*

Consistent with recommendations from MAC:SD's 2010 report and parents' perceptions illustrated by Barnard, Prior and Potter (2000), participants stressed that a positive approach to supporting behaviours must be adopted, staff must have appropriate training, and a multi-disciplinary approach needs to be employed (Ministerial Advisory Committee: Students with Disabilities 2010). The discussion paper for the Review of the Standards illustrates the necessity for raising awareness of disability issues amongst staff, addressing the barrier of attitude to equal access, as well as staff induction and professional development to be implemented (Department of Education, Employment and Workplace Relations 2010). These increased measures can be seen in the Positive Partnerships programs providing increased training opportunities for education providers, however, as one participant outlined, these opportunities are limited in rural areas for a multitude of reasons.

As another participant expressed, it is essential to take into account individual and environmental factors, 'while retaining a spectrum of provisions to match a spectrum of needs' (Connor 2006, p. 1).

5.2 Implications

Consistent with the limited research conducted on relevant areas, the overall responses from parents indicated a plethora of issues continue to face children with ASD accessing mainstream education. These issues range from exclusions taking place, to social and behavioural issues, to problems with specific teachers. Participants called for better resources, community education and tailoring individual programs, concurrent with recommendations from the Australian Autism Education Training Consortium (2008) that the ‘explicit teaching of social skills and a whole of school positive approach to behaviour support are recommended for children and students with ASD’ (cited in Ministerial Advisory Committee: Students with Disabilities 2010, p. 11).

Over half of participants identified education of teachers as crucial to achieving higher levels of inclusion and providing better support for children in the classroom. ‘Regular educational setting[s] will only be as effective as the staff who are responsible for the class’ (Connor 2006, p. 5), and the lived experience of the families involved highlight the extremely positive, or negative, effect that an individual teacher can have on their child’s schooling experience.

As highlighted by participants, inclusion can actually have a detrimental effect if a policy of inclusion ‘at all costs’ exists, and if inclusion means ‘little more than having the student physically present in the mainstream school’ (Connor 2006, p. 4). Instead, what is required is a system which has the ability to adapt itself to the student’s needs, ‘rather than expecting the students to accommodate to the demands of the school’ (Cutler cited in Connor 2006, p. 3). There is a current danger for the Standards to be misinterpreted, in some cases going so far as being used against a child to exclude them on the grounds of unjustifiable hardship, in what their parent described as discrimination. This highlights the need for policy developers to ensure that this legislation is not having an adverse effect and legitimising exclusion.

Chapter 6 - Conclusion

> *The Standards are intended to empower and educate those in the education and training sectors on how to be proactive in ensuring students with disabilities have equal access and opportunity in education, and helping to enable students with disabilities to achieve their educational objectives and goals and contribute to wider society in their chosen fields (Innes 2010, para. 8).*

Education providers have to strive to maintain an emphasis on inclusion whilst simultaneously allowing for the accommodation of individual needs of students with ASD (Ministerial Advisory Committee: Students with Disabilities 2010). There is a clear lack of research in this area and demand for appropriate services will continue as more and more children with ASD come through the mainstream education system. This study has shown the barriers which continue to face children with ASD in accessing mainstream schooling, despite measures such as implementation of the Disability Standards for Education. Exclusions are still taking place and families are required to act as advocates for their children to make sure inclusive practices are used.

With under-resourced schools, Standards being misinterpreted and such a variation in the commitment of teachers to inclusive practices, there is a pressing need for attention to be focussed on this area to ensure the needs of students with ASD are met and legislation is implemented effectively to reduce the number of students being excluded. This study is based on the experiences of 21 families, and although some findings correlate with previous studies conducted (eg. Humphrey & Lewis 2008a; Ministerial Advisory Committee: Students with Disabilities 2001b; National People with Disabilities and Carer Council 2009), the lack of specific research in this area highlights the need for further research to take place, on a larger scale and in different states, specific to ASD and the relevant legislation, the Disability Standards for Education.

6.1 Limitations

Despite the strengths of qualitative research in terms of depth of participant expressions and understanding of experience, there are limitations to this method. For example, the two key issues in qualitative research are said to be trustworthiness and credibility (Rubin 2000). These may be compromised by reactions generated by the presence of the researcher, bias in the way questions are asked and bias of responses because of social desirability of certain answers (Rubin 2000, p. 174).

Secondly, due to limitations in terms of resources and timing, the researcher was responsible for both conducting and transcribing interviews, as well as the analysis of responses in both the surveys and interviews. Transcribed interviews were sent to participants for comments and to provide an opportunity for any requests for the transcription to be changed before analysis was conducted, however the interpretation of the researcher and their bias is still a factor for consideration.

Interviews were conducted approximately a month after surveys were returned, but this varied due to respondents returning questionnaires in a staggered fashion and interview dates and times being limited, reducing the ability of the researcher to address the issues of trustworthiness and credibility through prolonged engagement (Padgett 1998).

Looking at a social constructionist approach (Crotty 1998), a limitation of the study is the inability of the researcher to interact with participants during the interview process without influencing them in some way. This was somewhat combated through the use of telephone interviews, reducing the level of immediacy and interference of factors such as body language. However, responses from the researcher throughout the interview still had the ability to influence the responses of participants and thus they cannot be analysed without taking into account the impact of the presence of the researcher.

Another potential limitation which could affect the validity of the study is that people who chose to participate in the research could have been motivated by a strong negative or positive bias, which they were eager to share through the interview process. Due to the title of the study and descriptions which different service providers sent out with the initial email asking for interest, those who had had a particularly positive or negative experience may have been more likely to share their experience. These participants may not be particularly representative of the wider community of parents with children with ASD at mainstream schools, and may have skewed responses. As already discussed, this may be reflected in the predominance of responses from parents of children with Asperger Syndrome.

6.2 Directions for future research

This study was small in size, and was limited to those participants with sufficient vested interest in the issue to initiate contact with the researcher. Future research should employ various means of recruitment, and on a larger scale, to ensure that an accurate and more representative response can be obtained. For an accurate picture of what is taking place in schools today, researchers have to include participants for whom the system is currently working well, together with those who are less satisfied. Larger sample sizes will give results a higher level of validity, as well as make conclusions more able to be generalised.

This study had a specific focus on South Australian participants, and the interest indicated by service providers from other states, as well as parents who were not able to be included, demonstrates the need for similar studies to be conducted throughout Australia. The current Review of the Disability Standards for Education will provide parents Australia-wide with an opportunity to provide feedback, however with the increasing numbers of children with ASD coming into and moving through the education system, there is a clear need for more research with a specific focus on ASD to help shape future policy direction and ensure education providers are able to provide quality, responsive and appropriate learning environments. It is hoped the findings of this study might contribute to this endeavour.

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CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

Dear Parent/Guardian

This letter is to introduce Ms Melanie Gorman who is an Honours student in the Department of Social Work at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis or other publications on the subject of the effect of the Disability Standards for Education (2005) on exclusion of children with Autism Spectrum Disorders from mainstream schooling.

She would be most grateful if you would volunteer to assist in this project, by completing a questionnaire which covers certain aspects of this topic. No more than half an hour would be required. If you are willing, a follow up interview, no more than an hour in length, will be organised to cover certain aspects of the topic in more depth.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make a tape recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed, and to make the recording available to other researchers on the same conditions.

If you are willing to be involved, please contact her at gorm0024@flinders.edu.au to commence the process.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 8201 2720, by fax on 8201 3760 or by email (fiona.verity@flinders.edu.au).

Thank you for your attention and assistance.

Yours sincerely

A/Prof Fiona Verity
Head
Department of Social Work and Social Planning

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5084). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

08/01/2011

Dear Parent or Guardian,

Thank you for agreeing to complete this questionnaire which forms part of my Honours research into the impact of exclusion of children with Autism Spectrum Disorders (ASD) from mainstream schooling, leading to the production of a thesis or other publications. With the number of children with ASD enrolled in schools expected to dramatically increase in the future and the lack of current research into how this is playing out in schools today, this is an important gap that needs to be filled. Gaining perspectives from those with lived experience is a crucial part of this, and your responses form an invaluable part of this understanding.

This survey asks you about the experience of your child in mainstream schools and will take you approximately 30 minutes to complete. Please feel free to add any information in addition to the questions provided if you wish on a separate sheet if necessary.

On completion of the project, I will provide all those who participate with feedback about the outcomes of the research.

Your participation is voluntary, and your family's confidentiality is taken very seriously. The following steps have been put in place to ensure confidentiality is maintained:

- **The questionnaire does not request your (or your child's) name, email address, postal address or other personal information.**
- **All information collected will be treated as private and confidential, in accordance with current privacy legislation.**
- **All completed questionnaires will be retained and will not be available for general view.**
- **At any stage, you may request that information be used in select ways. Similarly, you may ask for information to be omitted at any stage.**

You are free to withdraw from the project at any time without disadvantage and free to decline to answer particular questions.

This research project has received ethics approval from the Flinders University Social and Behavioural Research Ethics Committee. If you have any concerns about the project, my supervisor, Associate Professor Fiona Verity, can be contacted at Flinders University on 8201 2720 or fiona.verity@flinders.edu.au.

If at any time you feel that you have been adversely affected by taking part in this study, please contact the Autism SA Infoline on 1300 288 476 who will be more than happy to direct you to appropriate services for support.

I would appreciate if completed questionnaires could be returned to me no later than March 14th. Please forward your questionnaire in the envelope provided.

I thank you very much for your participation. Please contact me if you have any questions or concerns via telephone: 0400 159 135 or via email: gorm0024@flinders.edu.au.

Yours sincerely

Melanie Gorman
B. Soc. Work & Soc. Planning (Hons) Student
Flinders University

Exclusion of Children with Autism Spectrum Disorders from Mainstream Schooling

Section 1: About your child *(please tick one box in each section)*

1.1 Age of child / young person *(approximately)*

☐ 5-11 years *(Primary school age)*
☐ 11+ -16 *(Secondary school age)*
☐ 17-20

1.2 Current schooling

☐ Mainstream class/es at local school
☐ Mix of special class/es and mainstream class/es at local school
☐ Special school
☐ Child/young person has left school

1.3 Has your child been diagnosed with Asperger's Syndrome or 'High Functioning Autism'?

☐ Yes
☐ No

1.4 Does your child have a diagnosis of an Intellectual Disability along with an Autism Spectrum Disorder (ASD)?

☐ Yes
☐ No

1.5 Is any of the following extra support currently provided for your child in school:

☐ Full time helper
☐ Part time helper *If yes, approximate hours of help per week:* ______
☐ Facilitator as needed
☐ Specialist teacher
☐ Peer support
☐ No extra support

1.6 Do you believe the support provided for your child currently at school is appropriate?

☐ Yes
☐ No *If no, please explain why not:* ____

____

____

____

Section 2: Your involvement with your child's schooling

2.1 How much choice have you had in the past about which school your child attends?
(please select one of the following boxes)

☐ No choice ☐ Some ☐ A little ☐ A fair amount ☐ A great deal of choice

Comments: ______________________________

____

____

2.2 How often have you been involved in decisions about the education of your child?

☐ Never ☐ Sometimes ☐ Occasionally ☐ Fairly often ☐ Always

Comments: ______________________________

____

____

2.3 Has your child ever been excluded from school?

☐ Yes *If yes, please go to Q. 2.4*
☐ No *If no, please go to Q. 3.1*

Comments: ______________________________

____

____

2.4 Has this been informal or formal exclusion?

☐ Informal
☐ Formal

Comments: ______________________________

____

____

2.5 What effect did the exclusion have on your child's emotional wellbeing?

____

____

____

____

____

2.6 What effect did the exclusion have on your family overall?

2.7 How easy or hard has it been to get the child back into education?

☐ Very difficult ☐ Fairly difficult ☐ OK ☐ Fairly easy ☐ Very easy

Comments:

Section 3: Your child's experience of inclusive schooling

3.1 What does 'inclusive education' mean to you?

3.2 To what extent do you feel your child is currently included in school, or was included prior to their exclusion from school?

☐ No inclusion ☐ Some ☐ A little ☐ A fair amount ☐ Full inclusion

Comments:

3.3 Do you feel your child is (or was) actively included in lessons, formal activities or informal activities (eg lunchtimes) at school?

☐ Never included ☐ Sometimes ☐ A little ☐ Mostly ☐ Always included

Comments:

3.4 Are/were there any issues at school that affect/ed your child's access?

☐ Yes *If yes, please go to Q.3.5*
☐ No *If no, please go to Q. 3.7*

3.5 Please describe the type of issue that affected access
(eg physical access, social/emotional issues etc):

3.6 How were, or how could these issues have been effectively addressed?

3.7 Generally, to what extent do/did you feel that the teachers in the school are/were committed to inclusive education?

☐ No commitment ☐ Some ☐ A little ☐ A fair amount ☐ Fully committed

Comments:

3.8 How do/did you feel about the level of support available for your child at school?

☐ Not satisfied ☐ Partly satisfied ☐ Neutral ☐ Fairly satisfied ☐ Very satisfied

Comments:

3.9 Given your child’s experience, how effective do you believe inclusion in mainstream schooling usually is?

☐ Not effective ☐ Partly effective ☐ Neutral ☐ Fairly effective ☐ Very effective

Comments:

Section 4: Your understanding of school policies

4.1 Are (or were) you aware of any policies in your child's school about supporting all children to be included?

☐ Yes
☐ No
☐ Unsure

If yes, do you believe that the school upholds/upheld these policies?
☐ Yes
☐ No
☐ Unsure

If no, do you believe these policies need to be put in place?
☐ Yes
☐ No
☐ Unsure

Comments: ____
____
____

4.2 Are you aware of policies and legislation regarding inclusion that apply to all schools?

☐ Yes
☐ No
☐ Unsure

4.3 Do you think these policies have been effective in promoting inclusion?

☐ Yes
☐ No
☐ Unsure

Comments: ____
____
____

4.4 Disability Discrimination Standards for Education were brought in during 2005. Do you believe these have had an impact on inclusion of children with ASD?

☐ Yes
☐ No
☐ Unsure

If yes, in what way?

4.5 How do you believe children with ASD could be supported to feel more included in mainstream schools?

4.6 Any further comments or reflections of your experience around your child's schooling?

4.7 Are you willing to be involved further in this project through taking part in an interview at a later date?

☐ Yes
☐ No

If yes, please contact me via phone (0400 159 135) or email (gorm0024@flinders.edu.au).

Thank you very much for participating in this research.
Please forward your completed questionnaire in the envelope provided to
Melanie Gorman
'Effects of Disability Standards on exclusion'
Social Work and Social Planning, Flinders University
GPO Box 2100 Adelaide SA 5001
I would appreciate if questionnaires could be returned no later than the 14th of March.

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(by interview)

I …..

being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction for the research project on the effect of the Disability Standards for Education (2005) on exclusion of children with Autism Spectrum Disorders from mainstream schooling.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
   - I may not directly benefit from taking part in this research.
   - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I agree/do not agree* to the tape/transcript* being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed. ** delete as appropriate*

Participant's signature……………………………………Date…………………..

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………………………………….................

Researcher's signature………………………………….Date……………………

Interview topics

Main themes taken from questionnaire

1. About the child (diagnosis, school placement)
2. Participant's involvement with their child's schooling (level of choice/involvement)
3. Exclusion of child from schooling and effects on child/family
4. Child's experience of inclusive schooling
5. Understanding of school policies and impact
6. Recommendations for change
7. Reflections