

# **Experiences of School Choice and Change for Mothers of Students Diagnosed with Autism**

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# **Experiences of School Choice and Change for Mothers of Students Diagnosed with Autism**

## **Abstract**

This dissertation investigates the experiences of 22 mothers whose children diagnosed with autism were transitioning to school in Sydney, Australia. Qualitative interviews were conducted over three years (2009-2011) focusing on maternal experiences of school choice and change in the early years of formal education. Thematic narrative analysis of the interview transcripts (62 in total) is used to explore ongoing societal processes of stigmatisation and exclusion that shapes the lives of these families. A focus on maternal identity and gendered moralities underpins the analysis. Overall the six publications that comprise the core of this dissertation point to the constraints and dilemmas surrounding primary school placement and an ongoing drift towards segregated classrooms, especially for students diagnosed with both autism and an intellectual disability. The systemic failures to meet the promise of policies of school inclusion are demonstrated at the level of everyday practices by school gatekeepers, educators and bureaucrats. A variety of maternal tactics are deployed to manoeuvre and negotiate within an education field largely defined by professional and institutional strategies.

The dissertation is interdisciplinary, drawing on sociology, anthropology and critical disability studies. Theoretically the argument moves in two directions. Firstly, Goffman's conceptualisation of 'courtesy' stigma is reframed to more specifically account for the felt experiences of mothers. Secondly, maternal engagement with various forms of knowledge, both expert (professional guidance) and lay (rumour), is highlighted. Stigma and knowledge negotiation are intertwined in ongoing projects of school choice and school change which, in turn, shape and challenge identity at particular moments of maternal and student careers. School change narratives are used to invert the usual emphasis on the deficits of students diagnosed with autism focusing, instead, on maternal perceptions of the disabling practices of educators. The dissertation concludes with a case for conceptualising these widespread practices as Autism Inclusion Disorder.



## **Candidate Statement**

This thesis is submitted to Macquarie University in fulfilment of the requirements for the degree of Doctor of Philosophy in Early Childhood.

I certify that the material presented in this thesis has not been submitted, either in full or in part, for any other degree.

I also certify that the thesis is an original piece of research and is my own work. All sources used and assistance received in the process of researching and preparing this dissertation has been acknowledged.

The research presented in this thesis was approved by the Macquarie University Human Ethics Committee (Reference Number: HE27NOV2009-D00187) and Autism Spectrum Australia (December, 2009).

Signed:

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## Abbreviations

ABA	Applied Behaviour Analysis
ADHD	Attention Deficit Hyperactivity Disorder
AID	Autism Inclusion Disorder
ASD	Autism spectrum disorder
Aspect	Autism Spectrum Australia
BAP	Broader Autism Phenotype
CDWA	Children diagnosed with autism
CID	NSW Council for Intellectual Disability
DD	Developmental delay
DEC	Department of Education and Communities
DEEWR	Department of Education, Employment & Workplace Relations
DET	Department of Education and Training
DSM	<i>Diagnostic and Statistical Manual of Mental Disorders</i>
EI	Early intervention
EIP	Early intervention professionals
GPSC	General Purpose Standing Committee
GSDC	Government school disability consultants
HFA	High functioning autism
ID	Intellectual disability
IEP	Individual Education Program
IPESDSN	Inquiry into the Provision of Education to Students with a Disability or Special Needs
LSO	Learning Support Officer
NSW	New South Wales
PDDnos	Pervasive Developmental Disorder not otherwise specified
RDI	Relationships Development Intervention
SDID	School Disability Inclusion Disorder
SDWA	Students diagnosed with autism
SSP	School for Specific Purposes



# Chapter 1

## Introduction

### **Rethinking Autism: A Personal Story**

In 2007, before embarking on this PhD candidature, I interviewed Isabella<sup>1</sup> at her mother's house. Her three-year-old son, Stefano, had recently been diagnosed with autism, and she had kindly agreed to talk with me about the process of diagnosis and the therapies she was experimenting with. The house was tucked away in a sleepy suburban street. It had a reassuring solidity. Isabella was living at her mother's place because she and her husband were in the process of buying a new house. They needed to downsize to fund the substantial costs of daily in-home therapy (Applied Behaviour Analysis) for their son.

When Isabella opened the door she appeared anxious and busy. She ushered me into a formal parlour, decorated with her mother's embroidery work. A therapist was working with Stefano, in the adjoining room. They were watching a video featuring the popular children's character Maisy Mouse. As Maisy played with her animal friends, the therapist pointed excitedly to this menagerie, encouraging Stefano to make vocalisations.

Isabella had been a General Practitioner. With her son's diagnosis of autism and developmental delay, her world had irrevocably altered. She had given up all thought of working and her efforts were now entirely directed towards helping Stefano, with the hope of substantially improving his speech and social skills. She seemed both exhausted and highly concentrated on her task.

During the course of the interview we talked about the increasing prevalence of autism spectrum disorder (ASD). I asked her whether, as a doctor, she thought this prevalence pointed to a genuine rise in the number of children experiencing autism or was an artefact of diagnostic accretion and substitution. She replied: 'I think it definitely is increasing even though you can't convince the academics or the epidemiologists'. At this point Isabella looked around and said, with urgency, 'Because for me to know – I've got a photo somewhere'. She went to the entrance hallway and returned with a gilt-framed wedding portrait. Isabella explained that she was one of the bridesmaids. Then, sadly shaking her head, she told me that all four of the women in that

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<sup>1</sup> All names of people in this dissertation have been changed to preserve anonymity.



photo, all childhood friends, had children diagnosed with autism. ‘So nobody can convince me it’s not increasing’ she added.

That moment has framed my overall research on the experiences of mothers of children diagnosed with autism. Isabella’s emphasis on the importance of personal experience in forging maternal knowledge was repeated to me by different women over many years. So, too, were the unspoken elements of the interview – the pervading sense of loss and sadness; the terrible surprise that this particular child and this particular family had to deal with the ramifications of diagnosis; the determination to ‘turn things around’ and the fear of a future that might be defined by ongoing relations of mother/child dependency as well as discrimination and stigmatisation.

This dissertation is focused on a particular segment of the timeline of maternal care – the transition to primary school. The research presented here was guided by a major question: *What kinds of care, both pragmatic and affective, are mothers engaged in as they negotiate the transition to primary school of children diagnosed with autism?* In answering this question I have attempted to capture some of the striking contours of maternal experience at a critical juncture in the lives of children placed on the autism spectrum.

The pressing question of whether children should attend segregated classes with specialised instruction or enter the mainstream along with their same age peers has many ramifications, both for these students and for their families. Throughout this research I have tried to hold in mind the oscillations between despair and hope, exhaustion and determination, that are characteristic not only of Isabella but of all of the women I have met who are mothering children diagnosed with autism. The transition to primary school is preceded by other major transitions.

Firstly, there is the upheaval of diagnosis, which marks the beginning of maternal efforts to understand more about their child’s impairments and to come to terms with a radically altered sense of their own responsibilities and of future trajectories. This is generally followed by a shift in maternal identity as women struggle to overturn the bleak prognosis of ‘lifelong neurodevelopmental disorder’. In attempting to do so, they engage with therapies designed to ‘fix’ or, at least, ‘improve’ their child. As they assert the hopeful possibilities of the future they both engage with prevailing clinical views about autism and struggle against disabling discourses and practices that devalue their child.

When Isabella and I discussed autism prevalence in 2007 we had no idea that it would continue to increase so rapidly. Autism was first recognised as a coherent disorder by psychiatrist Leo Kanner in 1943. At that time, it was viewed as an extremely rare form of emotional

disturbance. Nowadays autism is a commonplace component of the developmental landscape (Liu, King, & Bearman, 2010). Talk of an epidemic is frequent. Popular magazines run headlines about ‘the autism generation’ (e.g. Milligan, 2012; see Jones & Harwood, 2009); screening instruments are devised to check for autism in toddlers (Baron-Cohen et al., 2000); therapies proliferate; schools have special classes for students diagnosed with autism. At present the most commonly cited conservative figure is that one in every 100 people has some form of autism (Walsh, Elsabbagh, Bolton & Singh, 2011).<sup>2</sup>

My research was prompted by my own son’s diagnosis with autism in 2004. An experienced psychologist made a home visit and the diagnosis that had been previously flagged by speech pathologists, a developmental paediatrician and a multidisciplinary team at a disability assessment unit was finally presented to me in black and white. It was my 42<sup>nd</sup> birthday.

In her report the psychologist wrote:

Oscar fulfils the diagnostic criteria for Autism Spectrum Disorder. The following criteria are confirmed in his presentation across all environments and observations: Qualitative impairments in reciprocal social interaction as manifest by; failure to adequately use eye contact; failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships; a lack of socio-emotional reciprocity.

Qualitative impairments in communication as manifest by; a lack of social usage of whatever language skills are present; poor synchrony and lack of reciprocity in conversational interchange; a relative lack of emotional response to other peoples’ verbal and non-verbal overtures.

Restricted, repetitive and stereotyped patterns of behaviour and activities as manifested by; a compulsive adherence to a few specific, non-functional routines or rituals; stereotyped and repetitive motor mannerisms; distress over change.

Oscar was three years and eight months old. Even though I had sought the formal diagnosis to ensure his eligibility for waiting lists for autism-specific schooling, the stark fact of autism

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<sup>2</sup> As I write this, the Centers for Disease Control and Prevention (Baio, 2014) in the United States have reported an autism prevalence rate of one in 68 children aged 8 years. Because the rates of diagnosis are much higher for males (4.5:1) this means that in the U.S.A. approximately one in 42 boys are currently diagnosed with autism. This represents a 30 per cent increase in prevalence from the 1 in 88 children reported by the CDC in 2012 (Willingham, 2014).

diagnosis was a moment of grief for our whole family. Being told that your child has a lifelong neurodevelopmental disorder is deeply difficult. Although the child in question has not changed, the label of autism, and the certainties of categorical reasoning that it both threatens and promises, alters everything (see Pilgrim, 2007).

I have previously written about some of my family's experience with diagnosis (Lilley, 2009a) and schooling (Lilley, 2009b) for popular parenting magazines in Australia. My husband, too, has published on the familial contexts of disability and the ways in which being Oscar's father has forged his interest in the ethics and politics of disability (Maclean, 2013). Like many other disability scholars, my commitment to research in this field is thus grounded in first-person experience (see Ginsburg & Rapp, 2013a, b). Our son, however, does not appear directly in the published articles that form the substantive content of this dissertation.

My approach has been to listen to the stories of other mothers and to place those narratives within a broader socio-political frame. In doing so, my aim is not to make a contribution to clinical understandings of autism. Rather, I hope to shed some light on maternal experiences of autism in everyday interactions, especially those encounters that bridge the space between social institutions and the intimacies of family life.

My background is in social anthropology. The training involved in becoming an anthropologist is, in large part, one of learning to problematise and relativise the taken-for-granted. Although this orientation did not protect me from the grief of autism diagnosis, it did allow a sustained intellectual curiosity about some of the striking features of the autism landscape as I experienced it. One of these features is that most of those caught up in what sociologist Gil Eyal and colleagues (2010) have termed 'the autism matrix' (including clinicians, therapists, educators, parents, diagnosed individuals and researchers) talk and behave as though autism is a straightforward fact, a discrete entity that can be recognised and treated.

If we look beyond our own backyards and clinics, however, we find that autism does not exist everywhere; there are many cultures that do not codify the behaviours, skills and incapacities we associate with ASD as either a disorder or a 'syndrome' (Ochs, Kremer-Sadlik, Sirota, & Solomon, 2004). In other words, autism, like all diagnostic entities, is a social construct. We need to be clear here. A diagnosis of ASD references real behaviours, oddities and impairments. But such behaviour is not everywhere grouped together under the rubric of 'ASD'; nor does it everywhere carry the same salience (Grinker, 2007).

In Australia ASD is diagnosed using the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) published by the American Psychiatric Association. This manual covers all mental health disorders of both children and adults and is generally considered the ‘bible’ for any professional making a psychiatric diagnosis. In a spirit of scepticism, Pilgrim (2007, p. 538) describes this weighty tome as ‘a revisable political manifesto for the psychiatric profession’. What Pilgrim is getting at here is the extent to which the labelling of all mental disorders requires an act of diagnostic reification wherein an individual’s experiential idiosyncrasies are codified. A diagnosis of autism, like other mental illness diagnoses, is overwhelmingly symptom based. In other words, a professional makes a diagnosis of ASD primarily on the basis of what a child does and says, and on what that child’s parents report. As Littlewood (2002, p. 191) helpfully reminds us, ‘psychiatric illnesses are not natural entities but rather observed concurrences’. The same can be said of autism.

Once my son was diagnosed, I began the arduous task of finding out about and accessing services and therapies in my home city, Sydney. I found early intervention frequently puzzling. I felt suspicious of the certain divides between the normal and the abnormal that were casually invoked as part of treatment strategies. I encountered novel ways of classifying the immediate world. Rooms were redescribed as ‘sensory environments’; therapies promised to ‘reconnect neural pathways’. Of course some of this was familiar. Certainly, the bureaucratic impulse to demand yet another piece of paperwork or telephone call in order to sit on a waiting list is nothing new. But the extent of these demands was astonishing.

The unfamiliar, too, was everywhere. Somehow I had never thought about children who could not speak. When my son began using sign language instead of speech I felt as though we had all travelled to a different land, losing many of our bearings along the way. The mothers I watched in neighbourhood playgrounds, who confidently called out to their children knowing a response would come, belonged to a once familiar world, a place where the metronome of developmental milestones and social achievements beat with a confident regularity.

This double sense of estrangement, both from the usual expectations of parenting and from many of the assumptions of the autism ‘scene’, prompted my first independent research, in Sydney, on the experience of mothers who have a child diagnosed with autism. It was as part of this project that I heard Isabella’s compelling story. In this early research, conducted in 2007 and 2008, I concentrated primarily on women’s experiences of diagnosis and early intervention. My research site was an early intervention centre, which offered services to children diagnosed with

autism and their families. There I observed playgroups and talked casually to mothers, some of whom I later interviewed.

Two publications arose from that independent research. The first (Lilley, 2011a) investigated the conflict and collusion between professional and maternal expertise in the process of autism diagnosis. Rather than explicitly rejecting a notion of their son or daughter as having a series of devastating deficits, as required by the diagnosis, mothers focused, instead, on the abilities that are often associated with autism. When mothers recounted their diagnosis stories to me they often insisted on the full personhood of their children and demanded that others acknowledge their intimate expertise in understanding that personhood.

The second publication (Lilley, 2011b) focused on some of the ideologies informing pedagogical efforts directed towards mothers of children diagnosed with autism in the early childhood years. The argument unfolded through contrasting the field of autism interventions (aimed at remediating perceived deficits) with workshops advocating inclusive education (designed to politicise mothers in relation to social justice and disability). I found that far from being passive recipients of the information given by service providers and advocacy groups, mothers actively negotiated the ambivalences and contradictions of autism 'knowledge' and the debates over personhood and community that such knowledge entails.

Having previously focused my independent research on diagnosis and early intervention, I decided to tackle the transition to primary school as experienced by families who have a child diagnosed with autism. Once again, this decision was informed both by my own experiences with my son and by my broader involvements in the autism matrix. When I enrolled in this PhD in early 2009 my son was attending an autism-specific 'satellite' or support class. He was in Grade Two and had begun his school career, in 2007, in an autism-specific special school. In 2008 he was moved to the support class because educators judged that he was able to participate in a more integrated classroom environment. In other words, we were immersed in the world of special or segregated education. My husband and I have parented three older daughters all of whom were considered 'gifted and talented' and attended a mix of neighbourhood mainstream primary schools and academically selective secondary schools. Special education was new to us.

During this period I served as a volunteer for a parent-to-parent telephone counselling service run by Autism Spectrum Australia. I also volunteered in my son's support class, mainly to provide one on one support for his efforts to attain literacy. I attended and spoke at panels organised to provide other families of children diagnosed with disabilities with first hand

accounts of their experiences with primary school. In the course of these activities I listened to many stories about the transition to primary school. Some were confident and cheerful; most were hedged about with doubts, difficulties and discriminatory episodes. All of these involvements contributed to the breadth of my knowledge base and a commitment to undertake further research on maternal experiences of primary school choice and change for students diagnosed with autism.

## **Contextualising the Research Project**

**Governing disability.** The Commonwealth of Australia consists of six states and two territories. Each state and territory maintains its own education system. In NSW, Australia's most populous state, both segregated (special schools and support classes) and mainstream schooling coexist. Studying the ways in which students are funneled into and out of mainstream and segregated schooling provides insights into the processes through which students experiencing disability continue to be sorted into different tracks early in their careers.

Over the course of my PhD candidature (2009-2014) many Government inquiries and reviews were undertaken that were relevant to issues of disability, care and education. In the main these information gathering and policy efforts arose from numerous complaints that the disability sector in Australia is grossly underfunded with an unwieldy and fragmented bureaucracy that does little to assist carers and has difficulty responding to people experiencing disability as individuals with the right to make their own decisions and choices.

Indeed, Australia has a dismal record in relation to disability. One report pointed out, for example, that Australia ranks very poorly in international comparisons in employment participation for the disabled with 45 per cent of people experiencing disability living near or below the poverty line (PricewaterhouseCoopers, 2011). In 2011 the systemic failure to address the needs and aspirations of people experiencing disability and their carers was documented in two key reports (Australian Government Productivity Commission, 2011; PricewaterhouseCoopers 2011), which estimated the disability services sector receives only half of necessary funding. Both reports pointed out that people experiencing disability are the largest minority in Australia and also one of the most disadvantaged groups.

In order to redress these inequities, a funding, support and governance mechanism known as the National Disability Insurance Scheme was proposed, which then passed through Federal

Parliament in March 2013. Support for this bill cut across party lines. It is widely viewed as the most significant social reform since the introduction of Medicare, Australia's universal health system, in 1975. Essentially the national scheme provides a universal no-fault insurance scheme for all Australians born with or acquiring a permanent and significant disability (Fanning, 2012a, 2012b). While doubts are currently being expressed about the long-term affordability of the scheme and its implementation, it has been encouraging to witness the largely positive reception to this reform. A sense that disability is suddenly on the front page and that the majority of Australians have a lot of goodwill towards improving the life possibilities for people with impairments through transforming an anachronistic sector is palpable.

In relation to education three recent reports are especially relevant to this study. The first was generated by the 2010 *Inquiry into Provision of Education to Students with a Disability or Special Needs* conducted by the NSW Parliament, to which I made a brief submission. This Inquiry found that many parents need to constantly advocate for the right of their child to receive the same educational opportunities as other children. An oft-repeated claim during the Inquiry was that one of the major barriers to the effective inclusion of students experiencing disability is the lack of appropriate funding across all sectors of the NSW education system. A 2012 NSW Government Inquiry found that the transition support service system for students with additional needs is fragmented and complex, and included recommendations to improve access to information and to establish more robust procedures for support and case management services.

Finally, a national *Report on the Review of Disability Standards for Education 2005* was also released in 2012 (Department of Education Employment & Workplace Relations (DEEWR), 2012). The Standards are designed as a mechanism for Government to achieve the objectives of the *Disability Discrimination Act 1992* in the education sector by clarifying the obligations of education and training providers to ensure that students experiencing disability can access and participate in education on the same basis as other students. Numerous submissions reported ongoing discrimination in all areas of education with some schools refusing enrolment of students with diagnosed disabilities (DEEWR, 2012).

Taken together, these Government inquiries and reviews documented widespread discriminatory processes and structures or 'disablism' (Thomas, 2004) in the education sector in NSW and in broader national contexts. They also suggest sustained policy concern and public interest in finding ways of improving the lives of individuals experiencing disability and their families. This wider context is a crucial backdrop to understanding the experiences of mothers

and their children diagnosed with autism as they navigate the difficult terrain of primary school transition.

**Autism: Changing clinical understandings.** The five-year span of this research project has also seen changes to the ways in which autism is categorised and diagnosed. As mentioned earlier, the clinical criteria in the American *Diagnostic and Statistical Manual* is generally used to diagnose autism in Australia. This manual is regularly updated. During the period of my research the DSM-IV-TR, introduced in 2000, was used (American Psychiatric Association, 2000). Under this classification children considered to be on the autism spectrum could receive one of three diagnoses – Autistic Disorder, Asperger’s Disorder or Pervasive Developmental Disorder not otherwise specified (PDDnos). The DSM-5, published in 2013 (American Psychiatric Association, 2013), folds these previously separate disorders into the single umbrella category of Autism Spectrum Disorder, with differing levels of symptom severity specified in the two core domains of 1) deficits in social communication and social interaction and 2) restricted repetitive behaviours, interests, and activities (Hyman, 2013; Wing, Gould, & Gillberg, 2011).

Along with changes in how autism is classified and diagnosed there have been other alterations to the way autism is understood. One of the most important of these changes concerns the relationship between autism and intellectual disability (ID). Not long ago it was common to state that 70% of people diagnosed with autism had a concurrent diagnosis of ID (IQ<70). That picture has changed remarkably over the last decades (Edelson, 2006). The most recent data from the Centers for Disease Control and Prevention (Baio, 2014) is that 36% of girls and 30% of boys diagnosed with ASD are also classified with ID. In other words, given the substantial prevalence difference between boys and girls (4.5:1), now almost 70 per cent of individuals diagnosed with autism do not have a concurrent diagnosis of ID.

Much could be said about the politics of the changing ways in which autism is clinically constructed and understood. For the purposes of this dissertation it is enough to note that a wide variety of children are being diagnosed with autism and that this diagnosis has profound effects on the way these children are perceived and treated. In Foucauldian terms it is extremely difficult to separate what we know about a category, in this case autism, from the various technologies that make it knowable (diagnostic manuals) or governable (including education ‘streaming’) (Allan, 1996; Tremain, 2005).



## Theoretical Orientations

**An autism lineage.** This dissertation is interdisciplinary. It draws on a wide range of theories and perspectives including disability studies, sociology, anthropology and inclusive education. As the prevalence of autism diagnosis has increased so too there has been a surge of academic publication and activity about autism (Mallett & Runswick-Cole, 2012). Much of this work is clinical or experimental, emerging from psychology, neuroscience and special education. While I have sometimes made use of these studies, this is not where my principal interest lies. The six publications aim to productively engage with academic debates and theory building around disability, autism, maternal care and inclusive education.

The perspective taken here has some affinity with ‘critical autism studies’ (Orsini & Davidson, 2013). Scholars within this frame draw on disability studies, especially in their questioning of prevailing deficit views of autism and in their interest in the intersections between autism and the broader social world. The fundamental distinction between medical (disability is located in the individual who needs fixing) and social models of disability (individuals have impairments but society creates disability), most forcefully articulated in disability studies (e.g. Shakespeare & Watson, 1997; Shakespeare, 2006), is a crucial starting point for understanding the processes of school choice, school placement and school change discussed in this research.

A number of books that might be placed within the ambit of critical autism studies explicitly address issues of autism and cultural production through the mediating lenses of narrative and representation. These include Mark Osteen’s edited collection *Autism and Representation* (2008), Stuart Murray’s *Representing Autism: Culture, Narrative, Fascination* (2008) and Patrick McDonagh’s *Idiocy: A Cultural History* (2008). These texts provide a valuable contribution to understanding the wider discourses and cultural tropes that inform social imaginaries of autism.

The research presented here is not, however, primarily concerned with issues of representation. It is most strongly influenced by anthropology and sociology, both in method (using an empirically grounded and localised study, which substantially draws on the perspectives of participants) and in the conceptualisation of the interplay between individual experiences and practices, and the structural constraints and possibilities of the social world.

As noted by Faye Ginsburg and Rayna Rapp (2013a), within anthropology disability has historically been located on the margins of medical anthropology. However in recent decades

disability has gained a more central position. This is largely due to research by parents who have become politicised about disability following their child's diagnosis.

Anthropology's founding fascination with human variability makes disability a compelling area both for its contribution to a broader understanding of human experience and its challenge to foundational Eurocentric assumptions about the link between autonomy and full personhood. The approach taken in this dissertation owes a special debt to Gail Landsman's (2009) ethnographic research on the perspectives of mothers of children experiencing disability in New York. Herself the mother of a daughter with cerebral palsy, Landsman provides extensive documentation of the ways these mothers and their children are positioned by cultural discourses that devalue them, as well as their creative responses to assumptions of diminished personhood.

A number of anthropologists, largely in the U.S.A., have contributed to revisioning autism through an anthropological lens. Roy Richard Grinker (2007), writing from his perspective as a father, has provided a cross-cultural look at autism combined with a moving autobiographical account of his daughter's growing competencies and the familial commitment to understanding and respecting her subjectivity. Olga Solomon, using her expertise in applied linguistics, has authored and co-authored numerous detailed studies of the ways in which children diagnosed with autism co-construct meaning and sociality across diverse relationships and contexts (e.g. Ochs et al., 2004; Ochs & Solomon, 2010; Solomon, 2004, 2008, 2012). From this empirically rich basis, she has gone on to argue the wider relevance of autism research to anthropology (Solomon, 2010).

Beyond anthropology, Majia Nadesan's (2005) book *Constructing Autism*, written from within a broadly Foucauldian perspective on biopolitics, has also informed my thinking. Nadesan is profoundly influenced by Ian Hacking's (1998, 1999) argument that psychopathologies, including autism, can be better understood by investigating the 'ecological niche' that allows the development of certain disease classifications, and by understanding the patterns and effects of some of these disease classifications through the notion of 'biolooping'. In applying the term ecological niche to autism, Hacking directs our attention to the socio-historical circumstances that lead some illness classifications to thrive while others fall by the wayside.

Nadesan, too, is interested in the 'historically specific niche conditions' (p. 27) that allow autism to thrive as a diagnostic category in the present. She argues that the expansion of both child psychiatry and mass public schooling were crucial to the process of identifying children who were deemed to be outside increasingly narrowly defined parameters of normality.

According to her constructionist argument both Leo Kanner (1943) and Hans Asperger (1944, translated Frith, 1991), the psychiatrists who respectively identified ‘autistic disorder’ and ‘autistic psychopathy’, created new labels to understand and treat children who would previously have been categorised differently, if they were noticed at all. Put simply, this suggests that it is the mechanisms of childhood surveillance, a vital part of the governance of modern states, which create categories requiring intervention and remediation. One of those mechanisms is schooling and one of those categories is autism.

Chloe Silverman (2013), in her book *Understanding Autism*, also offers a biopolitical analysis that directs the reader’s attention to the institutional and epistemological arrangements framing autism as a contested illness category, as well as the practices of experts and parents contributing to its continually changing contours. Her interest in the role of parent advocates in shaping autism is explored through the idiom of ‘love’. In the volatile field of autism, parental activism calls distinctions between experts and laypeople into question and also suggests that the emotionally neutral language of expertise masks the intense emotions motivating research and treatment.

Broaching these themes from a more distinctly sociological vantage point, Gil Eyal and colleagues’ densely argued (2010) book, *The Autism Matrix*, has been especially stimulating, providing a challenging text to think with and through, especially in relation to the sociology of expertise. Their description of the autism matrix as a network created and inhabited by children, parents, clinicians and therapists does much to convey the sense of the separate social world that is instantiated by autism diagnosis.

New articles and books about autism appear at a rapid rate. Academics, too, are part of the autism matrix and the research presented here can be seen as one small node in this continually expanding network. The autism lineage outlined above is, like all family histories, highly personal, reflecting my own experiences and biography. There is always more to add. But if the reader retains in distant view the multiple influences of anthropology, biopolitics and sociology on this work it may help to bring into focus the crisscrossing threads that together weave these collected publications into a coherent ensemble.

**Autism and maternal care.** Perhaps the most common question I have been asked at seminars and conferences when presenting this research is ‘Why are you only studying mothers?’ I address this issue throughout the articles presented. Nevertheless it seems worthwhile to answer this

question directly in these introductory remarks. As part of that answer I refer to some of the feminist theorising that has provided an indispensable scaffold to my thinking.

This dissertation is designed to elucidate the perspectives of mothers of students diagnosed with autism as they negotiate their child's transition to formal education. It provides insight into the ways in which autism is constituted because mothers are central to creating their child's social world, including therapy choices, involvement in school choices (and the consequent moulding of student careers) as well as the provision of daily care and love. It illuminates maternity through taking an explicitly feminist theoretical orientation concerned to articulate the mother as a subject in her own right engaged in a complex, conflictual and sometimes joyful process of acquiring the knowledge, the morality and the tenacity that underpins demanding care (see Hollway, 2006).

Acknowledging my own experiences of mothering a child diagnosed with autism, and the 'insider' perspective this allows on the experiences of other mothers, is an important component of my approach. My interest in maternal experience and autism is clearly compelled by autobiography. This runs the risk of being too caught up in my subject. By the same token, though, my continuing involvement with the very real set of practices and relations that are part and parcel of having a child diagnosed with autism in contemporary Australia, serves, I suggest, to deepen both my commitment and my understanding.

The research design focuses on maternal perspectives on children diagnosed with autism for two reasons. Firstly, in contemporary Australian society government agencies, social services, medical services and educational institutions all position mothers as the primary caregivers of children. Secondly, when a child is diagnosed with a disability, these expectations of maternal care, and culpability, are intensified. According to the Australian Bureau of Statistics, in 2003 in Australia 71% of primary carers were women. Primary carers aged up to 45 years are mostly mothers, looking after a child experiencing disability (House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009, p. 27).

Mothers of children diagnosed with autism are faced with a series of daunting commitments as they find they must navigate their way around services and treatments that are fragmented across bureaucratic systems and that compete over service provision boundaries and claims of superior efficacy and expertise (see Blum, 2007). Autism diagnosis thus has massive implications for family life, which generally increasingly pivots around the child while parents struggle with what Arthur Kleinman (1988, p. 27) aptly terms 'the resistance offered by profound

life experience’.

Disability research in the US has consistently demonstrated minimal paternal involvement in care for young children diagnosed with disabilities (Landsman, 2005). In her book, *Mothering Special Needs: A Different Maternal Journey* (2007), Anna Kingston has provided a similar picture for Ireland. As Christopher Gillberg (2007, p. 9) comments in the foreword:

... the difference is different in that such mothers, and such mothers only, are *expected* by legislators, doctors, psychologists, social workers, teachers and clergy, indeed by everyone to be the ultimate good mother, caring both *for* and *about* the child with the disability for the rest of their lives.

With rising autism prevalence rates a burgeoning academic industry has sprung up, collecting data on the parents of children diagnosed with autism. Research focusing on the experience of mothers of children diagnosed with autism has been dominated by a medical model, found in both the psychological and cognitive literatures, that has focused on either the deficits that parents share with their children, known as ‘the broader autism phenotype’ (e.g., Lainhart et al., 2002; Piven & Palmer, 1999; Piven, Palmer, Jacobi, Childress & Arndt, 1997), or on the burden and stress of parenting a child diagnosed with autism (e.g., Estes et al., 2009; Firat, Diler, Avci & Seydaoglu, 2002; Honey, Hastings & McConachie, 2005). The pathogenic emphasis of this literature has more recently been questioned by research that describes wide variation in parental adaptation to a child diagnosed with autism (e.g., Stanton, 2000).

The characterisation of maternal experience as either ‘disturbed’ or burdensome and stressful has been further questioned by a growing body of research that ‘proceeds from mothers’ own understandings of themselves and their children and documents mothers’ ongoing definitions and redefinitions of their experiences’ (Landsman, 1998, p. 73). Focusing on the ways in which disability is made sense of and understood within the everyday lives of people (see Ryan & Runswick-Cole, 2008), this strand of theorising is profoundly influenced by feminist scholarship (see Bassin, Honey, & Kaplan, 1994). It is this approach to understanding maternal perspectives on disability, and situating these within wider social and political processes, that I have adopted in this research.

There is a rich genealogy of scholar/mothers writing in this area. Making use of ethnographic approaches Rapp and Ginsburg (2001, 2011) have contributed insider insights to a critical anthropology that contributes to research demedicalising experiences of disability through

attention to the changing trajectories and innovative practices of families in the U.S.A. I previously mentioned the work of another anthropologist, Landsman, also writing about disability in the U.S.A. Her finely judged analyses of the social and emotional conflicts mothers find themselves caught up in and of the ways in which they react to pervasive cultural values that devalue both their children and their selves has been critical to my understanding of some of these processes in the Australian context (Landsman, 1998, 1999, 2003, 2009). This scholar/mother perspective also benefits Claudia Malacrida's (2003) sociological study based on the narratives of 17 Canadian and 17 United Kingdom mothers of children diagnosed with Attention Deficit (Hyperactivity) Disorder. Drawing on Foucauldian and feminist theories, Malacrida places mother-child and mother-professional relationships at the centre of her inquiry, providing a detailed sense of how mothers negotiate with/against representatives of the 'helping professions'.

In the Australian context, there is a limited literature on the experiences of parents of children diagnosed with autism. Building on David Gray's (1994, 1997) analyses of coping, stigma and family withdrawal, Andrew Cashin's (2003) doctoral dissertation attempted to answer the question: 'What is the lived experience of parenting a child with autism?' In pursuit of an answer, Cashin conducted nine interviews, with six mothers and three fathers of seven children aged four to ten years enrolled in an autism specific education setting in NSW, and convened four focus groups. Overall, he found that difficulties of the child with autism dominated family life resulting in intense emotional costs and reduced opportunities for all family members.

Cashin's characterisation of the experience of having a child diagnosed with autism is almost entirely negative. In a series of overwrought comparisons, he states that autism 'creeps into the selfhood of the parent not unlike a cloud of smog insinuating into a city on an otherwise cloudless day' (p. 133), that autism is a 'vortex into which the parents are sucked through the vehicle of the parent child relationship' (p. 135), warning of the danger of 'the complete absorption of the parent's self in the relatively existentially dangerous vortex core' (p. 157). Ultimately, this unrelenting negativity suggests caricature rather than careful analysis.

In her Australian research, Susan Tarrant (2002) is focused solely on maternal perspectives. Tarrant's qualitative study of 14 women parenting children diagnosed with high functioning autism in rural Victoria is, like Cashin's research, informed by a phenomenological approach. Tarrant identifies five major themes from an analysis of her interview data: a) acute frustration with services and systems along with unmet needs; b) family isolation; c) the

pervasive need for mothers to act as buffers between their children and a variety of disabling barriers; d) extensive personal costs and sacrifices; e) the persistence of chronic sorrow. Again, we are confronted with a largely negative picture of parenting a child diagnosed with autism. However, Tarrant's work is leavened throughout with a greater sense of the potential rewards of being the primary caregiver of a child experiencing disability as well as a more nuanced sense of the difficulties of such a role than is evident in Cashin's (2003) study. Once again, her 'insider' perspective, as a mother of a child diagnosed with autism, lends a credible depth to her analysis.

Taken as a whole contemporary scholarly literature on maternity and disability has pointed to the ways in which prolonged periods of child dependence often lead to constricted life possibilities for mothers. When this is combined with the social stigma that still surrounds disability, important questions about how caregiving is related to justice ethics and to highly gendered notions of citizenship and rights emerge (Hollway, 2006; Kittay, 2001). Part of the story of having a child diagnosed with autism involves mothers' efforts to come to terms with, and socially situate, their intensified caring responsibilities. As Silverman (2013, p. 6) gently reminds us, 'Caring labor most frequently falls to women, and because women are socialized to accept that obligation, they develop moral systems that are more attentive to matters of care and dependence.'

**Autism and education.** In NSW, as in other states and territories of Australia, there are broad legal and policy commitments to inclusive education. At the most basic level, this means that all students with 'special learning needs', including students diagnosed with autism, can and should be educated in the same settings as their typically developing peers, rather than being placed in segregated settings such as support classes or special schools. Inclusion is different from 'integration'. The latter typically involves integrating students only when they can demonstrate that they are able to successfully participate in the activities of the regular education class. This approach is often described as one of placing students in 'the least restrictive environment'. By way of contrast, inclusion advocates argue that students should not have to earn their placement in a regular class; that all children, whatever their level of need, should receive the necessary supports and services to allow them to participate fully in the activities of a regular classroom (see Carrington & Macarthur, 2012; Cologon, 2013; Slee, 2011).

A commitment to inclusive education is usually articulated within a social justice paradigm. Advocates also point to the pragmatic benefits of inclusion for all students. For those

experiencing disability the advantages may include more academic learning (Freeman & Alkin, 2000), greater self-esteem, a sense of community belonging, and the behavioural modeling of typical peers (see Mesibov & Shea, 1996; Rogers, 2000). For other students, inclusion is said to lead to a greater sense of empathy and social responsibility (Staub, 2005). For families of students diagnosed with disabilities inclusion is often represented as reducing stigma and social isolation (Centre for Studies on Inclusive Education, 2002; Cologon, 2013).

Nevertheless, many parents and educators continue to support an integrationist model of education, articulated within a needs paradigm that claims to prioritise the ‘best interests’ of vulnerable children (Ravet, 2011). This model is based on the provision of a continuum of education placements (from fully segregated special schools to support classes located within regular schools to enrolment in regular classrooms).

Education policy and practice varies throughout Australia. Currently in NSW many students experiencing disability are still being educated in segregated settings (Graham & Sweller, 2011). This is especially the case when students are judged, on the basis of psychometric assessments, to have an intellectual disability. Further, some students who are initially included in regular classrooms are later moved to either support classes or special schools (Bell & Dempsey, 2001).

The debate between inclusive and integrationist models remains especially heated in regard to students diagnosed with autism. ‘Challenging behaviours’, difficulties staying on task and distress caused by the busy social interactions demanded during a school day are often cited as reasons for placing these students in segregated settings. Special educators with expertise in autism often argue that smaller, highly structured learning environments benefit students with this diagnosis (e.g., Mesibov & Shea, 1996).

In NSW segregated classes or schools for students diagnosed with disabilities exist in all three sectors of the education system – Government, Catholic and Independent. The Government system has a limited number of autism-specific support classes while the Independent sector has two special schools (with vastly differing educational philosophies) that offer placements to students diagnosed with autism. These are Giant Steps (“Welcome to Giant Steps”, n.d.) founded by parents in 1995, and Woodbury, the first wholly Applied Behavioural Analysis based school in Australia, also founded by parents in 2006 (“Woodbury autism education”, n.d.). The largest provider of autism-only support classes and schools in the Independent sector is Autism Spectrum Australia (Aspect), with enrolments in 2014 of around 1000 students (“Aspect schools”,



n.d.). Students with a diagnosis of autism may also be enrolled in ‘multi-categorical’ (a wide range of diagnosed disabilities) special schools or support classes. When students have a concurrent diagnosis they may also be placed in schools or classes that group together individuals classified as having ID.

Further complicating this picture is the fact that even when a student is enrolled in a regular class in a mainstream school they may still experience forms of ‘micro-exclusion’ (Cologon, 2013). Forms of micro-exclusion include a refusal to make accommodations and an overreliance on teacher aides or frequent ‘pulling out’ of students for specialised teaching. In other words, enrolment in a mainstream school does not necessarily guarantee a welcoming environment in which institutional practices are designed to assist all diverse learners to participate and flourish.

If we look at what researchers have to say about the transition to school process for students diagnosed with autism, we find broad support for Bell and Dempsey’s (2001, p. 4) statement that ‘the determination of an educational placement may be one of the most important decisions of a child’s life and the choice of one type of setting over another may have immediate and long-term consequences’. As previously noted, in NSW ‘choice’ of setting is often a difficult and contentious process fuelled by the coexistence of commitments to inclusive education, especially at the level of rhetoric, with the ongoing existence of segregated education. Indeed this segregated system seems to be expanding (Graham & Sweller, 2011), and this may be partly due to the growing number of autism-specific classrooms and schools in NSW.

As Graham Foster (2005, p. 70) has observed, in relation to students diagnosed with autism in Queensland, until the education sector ‘gains a more intimate understanding of these students’ needs, it is likely it will continue to marginalise members of this cohort’. One way of gaining that intimate understanding is through the kind of longitudinal qualitative research presented in this dissertation. Talking to mothers at the beginning of their child’s formal education, and during the formative transition to primary school, offers insight into familial perspectives on the needs of students diagnosed with autism. This is a time in which patterns of interaction with educators and school bureaucracies are initially established. These patterns are likely to have ongoing ramifications throughout the students’ school careers.

The sociology of disability, which emerged most strongly in Britain in the 1980s, has directly challenged special education’s enduring emphasis on the remediation of individual deficits. A number of pivotal texts in this area have underlined the role of pervasive institutional

structures and practices in producing school failure, highlighting the ways in which race and class inequalities are reproduced through a focus on what is wrong with individual children (e.g., Barton, 1988; Tomlinson, 1981, 1982). Within this sociological tradition, Derrick Armstrong's 1995 book, *Power and Partnership in Education: Parents, Children and Special Educational Needs*, has been especially helpful. Armstrong contextualizes professional practices in the field of education within a frame that shows the interplay between the construction of 'deviant' childhood identities and the social structures producing those classifications. Most usefully, however, he argues that education is not only a form of social reproduction. Parent-professional interactions 'take place within a wider social context of competing and frequently conflicting interests' (p. 103). It is this broader sense of tensions and contradictions between different groups involved in primary school transition that I investigate, especially the relationship between mothers of children diagnosed with autism and education professionals.

Over the course of this research I have become increasingly familiar with, and influenced by, scholars whose writing explicitly supports, and interrogates, the movement for a genuinely inclusive education system that values the diversity of all learners in the regular school. In the Australian context, Roger Slee has produced an extensive body of influential work on these issues, directing attention to 'the gravity that pulls students to the centre or the margins of schooling, that includes or excludes' and the ways in which exclusion is buttressed by the continuing practice of sorting children into 'their allotted tracks' (Slee, 2011, pp. 138, 151). Suzanne Carrington has also made a substantial contribution to understandings of schools, diversity and inclusion (e.g., Keefe & Carrington, 2006; Carrington & Macarthur, 2012) with a particular interest in learners diagnosed with autism (e.g., Carrington, Papinczak & Templeton, 2003) and other developmental disabilities. Linda Graham's critiques of the ways in which schooling psychopathologises children thought to constitute a problem (e.g., Graham, 2007, Graham & Slee, 2008) as well as her efforts to concretely track processes of inclusion/exclusion in the NSW Government sector of the education system (Graham & Sweller, 2011) have also provided important perspectives.

Contemporary disability research has recognised the need to give parents of children diagnosed with disabilities a stronger voice (Briggs & Fisher, 2000). This is echoed by some education theorists. Slee (1996, 2011), for example, has argued that researchers need to tap into the authentic voices of students experiencing disability, their parents and advocates in shaping education policymaking. Listening to mothers (Read, 2000), in their role as mediators and

advocates for their children is, I argue, especially valuable in understanding experiences of school choice and change for students diagnosed with autism.

## Research Questions

This doctoral research, undertaken in Sydney, the capital of New South Wales (NSW), Australia, was, as previously indicated, guided by a major question: *What kinds of care, both pragmatic and affective, are mothers engaged in as they negotiate the transition to primary school of children diagnosed with autism?* The notion of ‘pragmatic care’ encompasses activities such as searching for a school, engaging in school processes (for example, attending meetings), and tackling bureaucracies in seeking further supports for children. ‘Affective care’ refers to the emotion work mothers frequently undertake on and for others (for example, dealing with the high anxiety levels of a child). The notion of pragmatic and affective care references the important work of Hollway (2006) on maternity and the ethics of care and provides a framework for thinking about mothers of children diagnosed with autism as engaged in a series of ethical activities and processes that are common to broader projects of maternal care.

Research sub-questions included:

*Has the broadly stated Government commitment to inclusive education made a genuine impact on schooling for children the students in this sample?*

*What factors are relevant for mothers in determining school choice and school placement?*

*How involved are families of children diagnosed with autism in both the transition to school process and ongoing relationships with schools?*

*Do mothers feel they and their child are subject to forms of social stigma during the transition to primary school?*

*When children are moved from one school setting to another, what factors have led to this change?*

For these mothers and their children transition to primary school is an important step and the stakes are high. Education is represented, in relevant clinical literature, as potentially the most effective ‘treatment’ for autism (e.g. Mesibov & Shea, 1996; see Ravet 2011. Parents are, therefore, especially concerned to make the right schooling ‘choice’. Although it is widely recognised that mothers are usually primarily responsible for caring for children diagnosed with ASD, especially in the early childhood years, there has been little research into their perspectives

on schooling and none that focuses exclusively on the transition to primary school. There is also a lack of substantive research tracing the early educational careers of students diagnosed with autism. This study helps to redress the paucity of qualitative research on these topics.

The research presented here is intended to deepen understandings of the barriers that continue to exist to inclusive education in Australia. At times, the articles that comprise the core of this dissertation make for depressing reading. The linked issues of the circumstances through which students diagnosed with autism are still placed in segregated education provision, the frequent inadequacies of mainstream provision and the exclusionary tactics of school gatekeepers are all profoundly political. Roger Slee (2011, p. 106) has made an impassioned plea for academic work that exposes 'networks of events, theories and practices that sustain exclusion'. This is a contribution towards that aim. But it is a contribution that also insists on the need to understand the perspectives of those most frequently charged with protecting and advocating for their children, mothers, and of recognising the constrained and difficult circumstances in which the politics of school 'choice' and placement are played out.



## Chapter 2

### Research Design, Methods and Sample

This research traces the early educational careers of students diagnosed with autism and documents the perspectives of their mothers as they negotiate their child's transition to primary school. The major question informing the research was *What kinds of care, both pragmatic and affective, are mothers engaged in as they negotiate the transition to primary school of children diagnosed with autism?* The design was longitudinal, with interviews taking place over a three-year period. Purposive sampling was used to access mothers whose children were enrolling in the full variety of available school placements for students experiencing disability in NSW - special schools, support classes in mainstream schools and regular classes in mainstream schools.

Ethics approval was granted in 2009 by Macquarie University (Ref: HE27NOV2009-D00187) and Autism Spectrum Australia (see Appendix 1). Part of the ethics approval included ensuring the anonymity of participants. Pseudonyms are used for mothers and their children. I have also changed the names of suburbs, early intervention centres, schools, other professional organisations and individual experts involved with these families. At times, non-essential biographical details have been altered or scrambled to further protect anonymity.

#### Recruitment

The participant criteria were as follows:

1. The mothers had children with a diagnosis of an ASD (Autistic Disorder, Asperger's Disorder or PDDnos) by a pediatrician and/or a psychologist.
2. The children were starting primary school in NSW in 2010.
3. The children were going to be enrolled in one of the three nominated educational settings (special schools, support classes or regular classes).

Participants were primarily recruited through early intervention providers, support groups for parents of children diagnosed with autism and Aspect. All of these organisations, most of which cannot be named for ethical reasons, were very helpful in passing on a recruitment flyer to mothers of children who met the criteria for this project (see Appendix 2).

Mothers who received this recruitment flyer then contacted me directly, either by email or telephone. Their reasons for participating were diverse. Certainly all of the mothers wanted to tell their story. Some were grateful to the organisations that passed on the flyer and saw their

participation as a form of goodwill. Some had read my journalism about mothering and disability and their participation was based on trust engendered by that writing. Some were uncertain about participating and phoned me to talk about the research, asking questions like ‘What good will it do?’ or ‘Why are you interested in this topic?’ When I told them that my interest sprang from my own experiences with my son, and that I hoped the interview material might have some impact on professional practice or policy, their hesitation was dispelled.

Once mothers contacted me and expressed an interest in participating I sent them an information pack (see Appendix 3). This included an interview schedule so that mothers had the option of thinking about the topics beforehand and of letting me know if there was anything they preferred not to discuss. When the signed consent forms were returned I organised a date and time for the first interview. Subsequent interviews were arranged via email or telephone. Interview schedules were also emailed prior to the second and third interviews. Some changes were made to the schedule for the third interview, based on emerging themes in the research (see Appendix 3). Participants also completed a demographic questionnaire (see Appendix 4).

My aim in the recruitment phase was to include an approximately equal number of mothers whose children were enrolling in segregated (support class or special school) or inclusive (mainstream) placements the following year. Recruitment continued until I had almost equal numbers of students in these categories, with 11 students enrolled in segregated settings, nine in regular classrooms and two unplaced in the first round of interviews. Those unplaced students were later enrolled in segregated settings.

Participants were free to withdraw from the research at any time. Twenty-two mothers agreed to participate in the first round of interviews, 21 in the second and 19 in the third. This was a better rate of ongoing participation than anticipated and explanations were not sought for attrition.

The decision to seek a relatively small sample was guided by the longitudinal nature of the research, involving three periods of data collection (62 semi-structured interviews). It was also guided by an anthropological sensibility, which specifically values depth and detailed description. The intimacy of the knowledge gained through this approach allows for a strong sense of the many variables shaping school placement decisions and of the emotional impact of ongoing forms of stigmatisation and exclusion.

Comparable Australian dissertations dealing with autism have, in general, small sample sizes. As previously noted, Tarrant (2002) undertook a qualitative study of 14 women parenting

children diagnosed with high functioning autism in rural Victoria. Cashin (2003) wrote about experiences of parenting children diagnosed with autism on the basis of four focus groups and nine interviews with six mothers and three fathers of seven children. Foster (2005) used a multi-case study approach to investigate variations in inclusive schooling practices as experienced by five male students diagnosed with autism and challenging behaviours in Queensland. Wright (2006) examined disability discourses surrounding five children labeled 'high functioning autism' in rural and regional NSW through interviews with teachers, parents, aides and the students themselves. Aitchison's (2006) study of school 'choice' involved 20 mothers in Sydney, including two with 'special needs'.

### **The Mothers**

The commonality between these mothers was that they each had a child diagnosed with autism who was about to start primary school in Sydney. This meant that they also shared many of the same experiences of dealing with the shock of diagnosis, accessing services and treatments in the early childhood years and looking for a school. In the process they all came into contact with the same types of professionals, such as developmental pediatricians, psychologists, speech therapists, occupational therapists, special educators. They also usually became acquainted with other mothers of children diagnosed with autism during these years. Their experience was often surprisingly similar in its basic contours, both at the level of pragmatics and of emotional responses to events and transitions.

As mentioned in the publications that follow, these women ranged in age from 29 to 48. The majority (15) were Anglo-Australian but a sizeable minority (seven) came from diverse cultural backgrounds. Sixteen of the mothers were very well educated, having completed university (12) or even postgraduate qualifications (four). Of these women, three trained as health professionals, three were qualified educators and one a practicing lawyer. Many of these mothers thus brought substantial cultural capital to their dealings with disability and education professionals.

Most of these women described their financial situation as adequate (13) or comfortable (five). Wealth, however, did not protect any of these mothers from the exhausting demands of navigating early intervention and school for their children or from the emotional impact of these experiences. But it did allow for more options in regard to both therapy choices and schools. Indeed the issue of differential access to resources and services is one of the serious issues raised



in this dissertation.

Available information about participating mothers is summarised in table form in Appendix 4.

## **The Children**

As noted earlier, the characteristics and abilities of children diagnosed with autism vary widely. My working assumption was that the differential placement of children on the autism spectrum would have ramifications for their treatment within the education system, which would, in turn, impact on the experiences of mothers. Consistent with the much higher ASD prevalence rate for males, mothers of 19 boys and three girls participated. The children of participating mothers reflected the heterogeneity of autism as a diagnostic category, meeting criteria for Asperger's Disorder, Autistic Disorder and PDDnos.

The students in this study were diagnosed using DSM IV-TR criteria. The majority (17) had received a diagnosis of Autistic Disorder; four met the 'weaker' criteria for PDDnos and one for Asperger's. Using DSM-IV-TR, Autistic Disorder applied to children who met the core criteria for autism (qualitative impairment in social interaction; qualitative impairments in communication; restricted, repetitive, and stereotyped patterns of behavior, interests, and activities or RRBs). Clinicians applied PDDnos, also sometimes known as 'atypical autism', when children did not meet sufficient criteria for a diagnosis of Autistic Disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology. A diagnosis of Asperger's Disorder was given when there had been no clinically significant delay in either language or cognitive development but significant impairments in social interaction and the presence of RRBs suggested markedly atypical development (see Mattila et al., 2011).

Depending on their performance in IQ tests, individuals diagnosed with autism are classified as either 'low functioning', 'borderline' or 'high functioning' and may even be variably placed on this continuum throughout their lifespan (McGeer, 2005, p. 100). These are not diagnostic categories. Rather they are labels used, often loosely, by parents and professionals as a quick typification that indicates where they perceive a particular individual to be placed on the autism spectrum. 'High functioning' is generally used to refer to individuals with an autism diagnosis who do not have a concurrent diagnosis of ID but who do not fit the criteria for Asperger's disorder (often due to delayed language acquisition).

Seven of the mothers had children with an additional diagnosis of moderate to severe

intellectual disability who were consequently described as ‘low functioning’, including two of the three girls. Six mothers had children they described as ‘borderline’ and nine had children described as ‘high functioning’ (eight) or Asperger’s (one). Once again, it is worth pointing out that I use this clinical terminology because these classifications have performative effects. In particular, a concurrent diagnosis of ID has a powerful effect on where students are placed and on how negative the perception is of their possible developmental trajectories.

It is also worth drawing attention to the fact that children’s placements within the spectrum of autism and intellectual disability classifications can change over time as they are reassessed. Also, some children have two concurrent assessments, which can result in different diagnostic placements across the spectrum. All of the classifications used here are based on maternal report. Where mothers have received differing assessments, or are simply uncertain about woolly clinical language such as ‘developmental delay’, they may choose to represent their child’s diagnoses in various ways depending on the audience and current circumstances. Inevitably, then, there is a contextual lability in maternal descriptions of clinical categorisations. While the researcher can temporarily ‘fix’ these categorisations, these fluctuations are properly seen as a property of the autism matrix.

## **The Interviews**

Participating mothers were interviewed up to three times. This ‘periodic reinterviewing’ (Handel, 1994, p. 79) was intended to enable a better understanding of trajectories of meaning and practices in relation to transition to primary school for children diagnosed with autism and their impact on maternal experiences. This longitudinal perspective assisted in understanding more fully the complexities of the transition process, as well as changes in education placement for students diagnosed with autism in the early years of primary school. It also allowed for the gradual construction of trust and rapport with mothers that, in turn, provided richer data.

Each interview had a different focus. The first interview took place a few months prior to primary school transition in 2009. Topics discussed included experiences of diagnosis, early intervention, processes of school placement and advice received. Interview two was conducted at the end of the child’s first year of formal schooling (Kindergarten in NSW) in 2010. The child’s experience of school, the changes to family life during this transition period, the extent of support received, as well as the mother’s relationship with school personnel and the wider school community were discussed. The final interview was at the end of the child’s second year of

primary school (Year 1 in NSW) in 2011. Previous interview topics were pursued, as well as any changes in school placement and the reasons for these.

The average length of interviews was 64 minutes. The shortest interview was 23 minutes and the longest 98 minutes. Some women were consistently chatty and tended to tell detailed stories. Others were less inclined to elaborate. All of the interviews (62) were conducted by the researcher. One of the participants, who is Vietnamese, required a translator. The other 21 mothers were all fluent in English.

Most of the women chose to be interviewed in their own homes. Often this was because they were caring for their child or children. These at home interviews were a valuable opportunity to gain some observational knowledge of the socio-economic status of participants and sometimes to meet other family members, including partners and children. Often insights about the extent of care mothers provided were gained by observing these interactions. Some attempted to juggle homework with interview participation; others had to pause while they helped their child with toileting or answered their questions about caterpillars gleefully brought in from the garden. Whether these mothers lived in a crowded apartment with three children underfoot or owned substantial houses, they were all unfailingly generous with their time and hospitality. Occasionally mothers chose, instead, a public place for the interview, electing to go to a café. One mother asked to come to my house, bringing her six-month old baby along with her.

The questions emailed in advance to mothers were used as a guide to ensure that the same topics were explored across cases for purposes of later comparison and generalisation. These questions framed the overall direction of the interviews but were sufficiently flexible to allow for the incorporation of new topics over time, as suggested by the responses of participants. In other words, the agenda was open to development and alteration, depending on the experiences of mothers and the kinds of stories they wanted to tell (Hollway & Jefferson, 2000). I adopted a conversational style and encouraged mothers to pursue topics they found relevant to their experiences of primary school transition for their children. Mothers were especially encouraged to discuss the extent to which they felt involved and empowered in educational decisions affecting their child.

Hollway and Jefferson (2000) have underlined the widely accepted point that qualitative researchers need to take seriously the intersubjective dynamics of the interview relationship and their own role in both the production and analysis of data. As I indicated earlier, my desire to

undertake this project grew from my own experiences with my son. When he was close to six, the legal age at which children have to attend school in NSW, I was brimming with anxieties and concerns. He did not use a toilet; he had limited speech that others found difficult to understand; he became easily overwhelmed by anxieties; he showed no signs of recognising the difference between a letter and a number; he had a fear of other children; he rarely sat still. At that time he was diagnosed with a mild intellectual disability as well as autism. In the end I gratefully accepted a place in an autism-specific special school. I simply could not imagine him going to a mainstream school.

When other mothers told me their stories of primary school transition, of their worries and their hopes and sometimes their anger, I listened with sympathy and respect. I did not know the full details of their stories, the unique character of their child, or all of the options and possibilities that had been opened up or closed off to them since their child's diagnosis. But I did know the overall shape of their stories because it is my story too. Identifying with their difficulties and successes helped me to be a good and empathic listener. Familiarity with local systems of service and education provision for children diagnosed with autism also allowed me to follow the ins and outs of maternal experiences.

The interviewing process was not always easy. Particularly when recounting diagnosis narratives, maternal feelings are intense. Tears are common. Mothers who care for children diagnosed with intellectual disabilities are often struggling with the intense care demands placed upon them. Their anguish is palpable.

Often the most revealing moments in the interviewer-participant relationship occurred after the recorder was turned off. Prior to the first interview I made an effort to disclose to all participants that I had a child on the spectrum. But I avoided giving any details about him unless I was questioned directly. After the interview mothers often asked for advice or for my opinion. They knew my son was a few years older than their child and figured I had valuable knowledge about therapies and schools both through my research and my parenting. Mostly I tried to remain neutral, offering only reassurance that these are difficult decisions for all families.

Sometimes, too, I struggled with my own feelings. On a couple of occasions I remained silent as mothers criticised, unknowingly, the very school setting I had initially enrolled my son in. 'I tell you what, I'm not sending my kid there to be babysat!' one announced. The feelings engendered by these kinds of remarks are difficult because the narratives of mothers are not just stories about their children. Each time a mother narrates an affronting incident, a choice made, or

a fork in the road they feel coerced to follow, they also tell a story about themselves. It is always the story of the good mother. Mothers who make different choices from them are implicated as mothers lacking in judgment or tenacity. In these interview situations a sense of humour and some fortitude are requirements of the research task.

The longitudinal design of this research was crucial in building trust and rapport across the three-year interview period. The high percentage of women who agreed to be interviewed again each year attests to the success of that relationship and to their desire to speak to a sympathetic listener who was not embroiled in the immediacies of their lives. Sometimes women told me the same story again and again, especially when particular events had been troubling for them and they were trying to process their feelings and retrospectively assess the situation.

Each year these tales would change slightly in tone and in tenor as mothers shifted their perspectives or reframed an event to be more emotionally tolerable. This was especially the case with very upsetting events – moments when mothers felt their family was stigmatised and the full personhood of their child had been questioned. Psychometric evaluations, for example, inevitably provoked strong emotional responses that often take years to work through.

One of the enduring pleasures of interviewing mothers over three years has been listening to what Mattingly (2010, p.31) calls ‘anticipated stories’. These are stories that speak to what participants imagine will come to pass – their child’s first day at school; their child’s acquisition of language; their child’s ability to make friends. Not all of these anticipations occur. But, on occasion, I listened as the future became the past. The anxieties of the first year of primary school were replaced by other hopes and worries as children developed and parents embraced new projects and aims to keep pace with them. It is a privilege to move momentarily along segments of a timeline with a family. It is also valuable to research, allowing some understanding of how processes unfold over time and of how the life possibilities and identities of both mothers and children are forged in that process.

## **The Analysis**

Following each interview I wrote a brief pen portrait of the participant, the current school setting of their child, any major concerns expressed or incidents described. The purpose of writing these fieldnotes while the interview was still fresh in my mind was to convey an overall impression of the interview and of the attitudes of the participant, to which I could later refer.

I then downloaded the audio onto my computer and listened to the entire interview. While

listening I wrote down as much of the detail of the interview as I could type without pausing the recording. This created a longer summary with some direct quotations. Reading over the longer summary and the fieldnotes I created a list of themes emerging from each interview. This process of thinking about themes and substantive patterns in data also occurred at the pre-interview phase (when constructing interview topics and schedules on the basis of prior knowledge gleaned through both scholastic reading and experience of the local autism matrix) and during interviews.

Most of the interviews were fully transcribed using the services of a professional company. However when the audio quality of interviews was poor because of constant interruptions or ambient noise I undertook the transcribing myself. Being present at the interview, and familiar with the accent and cadences of the interviewee, greatly aided my comprehension of the recording.

When I had a complete transcript, I checked it for accuracy and then anonymised the contents through, for example, altering names and places. The anonymised transcript was sent to each mother for checking. At this stage, participants were told that they could request the removal of any material they did not wish to be included as part of the research data. No requests for the excision of any interview material were received throughout the duration of this project.

The themes emerging from the interviews strongly influenced the choice of research topics appearing in the following publications. Once I compared themes across interviews, this method of proceeding generated literally dozens of ideas for research articles. For example, randomly choosing four consecutively listed themes from one interview, generates the following list: ‘combative funding meeting: the mother as bureaucratic warrior; constructing child as worse to attract funding; juggling work and motherhood; disclosure: husband and wife conflict over.’ Only one of these themes – ‘constructing child as worse to attract funding’ – appears in a publication.

Once I decided on a publication topic, I reread all of the relevant transcript material and extracted segments of narrative that might illuminate the issue being investigated. I use the word ‘relevant’ because not all interviews were used for each topic. For example, the first publication uses nine cases of mothers who initially enrolled their children in segregated settings. To write this chapter I tried to hold the contextual material contained in the whole data set in mind but only needed to extract material from nine interviews. By contrast, when I wrote the fifth publication exploring the different forms of professional guidance negotiated by mothers I needed to reread and extract material from the entire set of 62 interviews.

Rather than fragmenting data using code and retrieve methods (Hollway & Jefferson, 2000), the principle I followed was to work with the whole data set, immersing myself in the interviews as I began thinking about each new publication. While keeping each whole case in view has been time consuming it has allowed a strong contextual sense of why decisions were being made and of the wide range of attitudes and processes that inform smaller narrative segments. This process of rereading transcripts, removing (disassembling) bounded narrative segments that were related to specific topic and then returning to the original data set each time I began another topic allowed a continuing connection to the material as a whole (see Yin, 2011). Indeed, at times my imagination has felt full of the lives of the 22 mothers interviewed. Hollway and Jefferson (2000, p. 69) refer to this sense of imaginative saturation as necessary component of a theoretical commitment to holistic interpretation.

The broad method I have followed in tacking between immersion in the entire data set and analysis of segments that are relevant to particular topics is thematic narrative analysis (Riessman, 2008). In common with other researchers using this method, I have been more interested in thematic meanings, or the content a narrative communicates, than in the form or structure of the narrative. My main procedure has been to generate thematic categories across individual cases while still preserving individual stories. As Reissman (2008, p.74) explains: 'Theorizing across a number of cases by identifying common thematic elements across research participants, the events they report, and the actions they take is an established tradition with a long history in qualitative inquiry'.

Put more formally, once I identified a topic and subsidiary themes I then extracted bounded segments of interview text about incidents or feelings pertaining to that topic and themes. These smaller segments, positioned within larger stories, are the narratives I worked with. My analytic focus was largely on recurrent attitudes or episodes across narratives (for instance, narrated episodes of exclusion from schools). However, I was also interested in the subjectivities of mothers as they reflected on their own and their child's experiences.

I educated myself about contexts by reading scholarship that bears on the topic being investigated. Each time I began a new chapter or article I read widely in that area. That reading sometimes took the form of more general theory and sometimes was specifically about local contexts. The sixth publication, on maternal rumour, provides a neat illustration of this. After extracting all of the relevant narrative segments from the primary data set I then read numerous secondary sources. Some of these were general theories about rumour from philosophical,

sociological or anthropological traditions. Others were Government inquiries or local reports that touched briefly on the topic. In my writing I then tack back and forth between my primary data and the scholarship of others, checking the themes emerging in interviews (e.g. rumours about the dangers of mainstream schools) against concepts others have elaborated (e.g. rumour as a form of conservative moral policing).

Perhaps the exemplar that has most influenced my thinking about method is Tina Miller's (2005) *Making Sense of Motherhood: A Narrative Approach*. Her book explores women's own accounts, over time, of their experiences of transition to first-time motherhood. In particular, her attention to the disjuncture between personal experiences and dominant public discourses, as well as to the cultural dimensions of expert knowledge, have resonated with themes of this research. Inevitably in the course of my own writing I had to make choices about which topics to focus on, keeping in mind the aim of creating a consistent body of research that gels together as a whole. To this end I have mainly concentrated on maternal experiences of school placement and choice as well as school change for children diagnosed with autism. However, there remains a vast body of narratives about mothering practices contained within these interviews that awaits later thematic analysis.

Longitudinal interview studies and thematic narrative analysis are now used in many disciplines. The ways in which my own family narrative intersects with the stories of the participants in this study is sometimes called 'insider anthropology' or 'anthropology of home' to refer more broadly to people doing research in their own communities (Peirano, 1998). As Landsman (1998, p. 76) has argued, being both an anthropologist and the mother of a child experiencing disability makes the researcher part of a shared 'community of experience' based on altered expectations of biographical trajectories and consequent transformations in maternal identity. My approach is ethnographic in that the framing of the interviews and the work of analysis have both been substantially informed by my own 'local knowledge', (Geertz, 1983) gained over years of immersion in the autism matrix as both a mother and a researcher. The effort to contextualise these narratives within wider sociopolitical and cultural frameworks and to provide 'thick description' (Geertz, 1973, Chapter 1) (in this instance, grounded in my experiences of the lifeworlds of mothers of children diagnosed with autism) are fundamentals of anthropological approaches.



## The Publications

There are six publications presented as the core of this dissertation. They appear in the order in which they were written. All are informed by the major research question: *What kinds of care, both pragmatic and affective, are mothers engaged in as they negotiate the transition to primary school of children diagnosed with autism?*

The primary emphasis of the interview questions was on pragmatic care, especially the negotiation of different sources of knowledge, as mothers tried to find a suitable school for their children. However the issue of ‘affective care’ remains crucial in framing maternal decisions and reactions. Mothers try to ensure the emotional wellbeing and safety of their children and often feel they are doing so in adverse circumstances. They are also engaged in projects of self-preservation, of looking after self, in perceiving and representing themselves as good mothers in the face of stigmatising actions and attitudes.

1. The first publication is a book chapter titled ‘Mind the gap: Maternal perceptions of segregated school “choice” for students with autism in New South Wales primary schools’. It was published in a collection edited by Peter Whiteman and Katey De Gioia (2012) titled *Children and Childhoods 1: Perspectives, Places and Practices*. This collection arose from a symposium held at the Institute of Early Childhood, Macquarie University, Sydney, in 2010. In this chapter I address the research sub-question: *Has the broadly stated Government commitment to inclusive education made a genuine impact on schooling for the students in this sample?* In considering this question I investigate why mothers continue to enrol their children in segregated settings.

2. The second publication, ‘It’s an absolute nightmare: maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia’, appeared in 2013 in the journal *Disability and Society*. This article explores maternal narratives of informal school exclusion using interactionist theories of stigma and disability, derived, in large part, from Erving Goffman’s (1963) classic contributions to this field. As was the case with the first publication, this article also draws on material in the first set of interviews, which were conducted in 2009 as children were about to enter their first year of formal education.

3. The third publication, ‘Crying in the park: Autism stigma, school entry and maternal subjectivity’, came out in 2013 in an online feminist journal *Studies in the Maternal*. Here I extend the theorising around stigma and autism. The emphasis, however, is different from the previous publication. Whereas ‘It’s an absolute nightmare’ dealt with the stigmatising practices

or strategies of schools, this publication looks in much greater detail at how stigma impacts on maternal subjectivity, making use of feminist theorising around motherhood as well as previous scholarship about mothers of children diagnosed with autism. How can we build on extant theories of stigma, I wonder, to better understand the experiences of these mothers?

4. The fourth publication, 'Professional Guidance: Maternal negotiation of primary school placement for children diagnosed with autism', appeared in 2014 in the journal *Discourse: Studies in the Cultural Politics of Education*. This article explores the ways mothers engage with or reject expert advice about school placement. This is the first of the publications to make use of the longitudinal design of the research, drawing on all three sets of interviews. It addresses the research sub-questions: *What factors are relevant in determining school choice and school placement?* and *How involved are families of children diagnosed with autism in both the transition process and ongoing relationships with schools?* Using Gil Eyal and colleagues' (2010) model of the autism matrix as a comparative point of reference, I explore the issue of the relationship between professional expertise and maternal agency.

5. The fifth article, 'Rumour has it: The impact of maternal talk on primary school choice for children diagnosed with autism' is published online in the *International Journal of Inclusive Education*. Again, this article speaks directly to the question of how families make choices between segregated and mainstream options. It, too, provides a longitudinal perspective making use of the entire data set. Focusing on informal talk between mothers, or 'hot knowledge', as an important component of the decision-making process, this publication forms a pair with 'Professional guidance'. Together they provide a fuller picture of how mothers negotiate multiple forms of knowledge during periods of school transition and of the importance of these processes in forging maternal identity.

6. The sixth and final article presented as part of this dissertation is 'Trading places: Autism Inclusion Disorder and school change'. At the time of writing, it has been accepted, subject to minor revisions, by the *International Journal of Inclusive Education*. This publication directly addresses the sub-question *When children are moved from one school setting to another, what factors have led to this change?* Using the narratives of eight mothers, the paper documents and analyses the circumstances leading to school change in the early primary years.

Together these publications make an original contribution to our understanding of the types of knowledge and social practices that contribute to school choice and placement, as well as the exclusion and the stigmatisation of students diagnosed with autism. While the research is set

in NSW, the theoretical arguments about stigma as well as documentation of the day-to-day practices that contribute to disabling attitudes are broadly relevant to many other places. Further, although this thesis is focused on autism these publications speak, in their broad contours, to the experiences of all children diagnosed with disabilities who find they live in societies that devalue and discriminate against them.

The research also makes a distinctive contribution to our scholarly understandings about mothers of children diagnosed with autism. Much of this echoes previous work on motherhood and disability, as outlined earlier in the Introduction. But I trust, too, that the specificity of these narratives, which trace the possibilities and limits of maternal agency, as well as the deep impact of stigma on maternal subjectivity, also amplify previous scholarship, providing another layer to our understanding of the lived experience of families struggling to care for and about their children in the midst of difficult social circumstances.

Because this is a dissertation by publication there is some repetition in the publications regarding the sample, the methodology and the broader social context of the education system in NSW. It was necessary to give each new set of readers some knowledge of these aspects of the research. Due to the strict word limits of the journal articles, a fuller discussion of the design of the research project, the sample and the methodology has been provided in these introductory chapters.

Some patience is also required on the part of the reader regarding stylistic inconsistencies across these publications. I have tried to disseminate this research across a broad range of journals. They all use different style guides. The chapter and journal articles are reproduced in their original published form.

## **Chapter 3**

### **Publication #1**

#### **Mind the Gap: Maternal Perceptions of Segregated School “Choice” for Students with Autism in New South Wales Primary Schools**

**Chapter 3 - pages 38-56 of this thesis have been removed as they contain published material under copyright. Removed contents published as:**

Lilley, R. (2012). Mind the Gap: Maternal Perceptions of Segregated School “Choice” for Students with Autism in New South Wales Primary Schools. In P. Whiteman & K. De Gioia (Eds.), *Children and Childhoods 1: Perspectives, Places and Practices* (pp.58-74). Newcastle upon Tyne: Cambridge Scholars Publishing.

## Chapter 4

### Publication #2

#### **It's an Absolute Nightmare: Maternal Experiences of Enrolling Children Diagnosed with Autism in Primary School in Sydney, Australia**

Published as:

Lilley, R. (2013). It's an absolute nightmare: Maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia. *Disability & Society* 28(4), 514-526. doi: 10.1080/09687599.2012.717882

Post-publication abstract correction:

In this article I analyse maternal narratives of informal school exclusion at the point of transition into primary school in Sydney, Australia. The common thread that connects these narratives is the experience of stigma. Some scholars have argued that the link between stigma and disability is weakening. The material presented here, drawn from interviews with 22 mothers of children with autism, gives a picture of the continuing pervasive stigmatisation of children with autism and their mothers, as well as a systemic failure of all sectors of the education system in Sydney, New South Wales to meet the promises of policies of school inclusion.



# **It's an Absolute Nightmare: Maternal Experiences of Enrolling Children Diagnosed with Autism in Primary School in Sydney, Australia**

In this article I analyse maternal narratives of informal school exclusion at the point of transition into primary school in Sydney, Australia. The common thread that connects these narratives is the experience of stigma. Some scholars have argued that the link between stigma and disability is weakening. The material presented here, drawn from interviews with 22 mothers of children with autism, gives a picture of the continuing pervasive stigmatisation of children with autism and their mothers, as well as a systemic failure of all sectors of the education system in Australia to meet the promises of policies of school inclusion.

**Keywords:** autism; education; school; exclusion; transition; stigma; inclusion; mothers

## **Points of Interest**

- This paper reports on qualitative, longitudinal research on the transition of children with autism to primary school in New South Wales, Australia.
- This paper documents the systemic failure of all sectors of the education system to meet the promises of stated policies of school inclusion, and the continuing stigmatisation of children with autism and their families.
- This paper contributes to knowledge of sustained and ongoing exclusion practices in education, especially the role played by school gatekeepers at the point of enrolment to primary school.
- This paper features the voices of mothers of children with autism, and analysis of maternal narratives.
- This paper deepens our understandings of the difficulties faced by families of children with autism, especially maternal experiences with 'experts'.
- This paper engages with theoretical debates on the relevance of stigma as an explanatory frame in disability studies.

## **Introduction**

In this article I analyse maternal narratives of informal school exclusion at the point of transition into primary school in Sydney, Australia. The common thread that connects these narratives of attempted school exclusion is the experience of stigma. When mothers of children diagnosed with autism recount their experiences with school administrators, principals, teachers and other gatekeepers, we often hear stories of stereotyping, discrimination, and efforts to informally exclude, frequently dressed in the bureaucratic language of inadequate resources and encouragement to look elsewhere. These attempts to relegate children identified with autism to 'less desirable environments' create what David Sibley (1995), in another context, has termed 'landscapes of exclusion' (see Ryan 2008, 730). Within this bleak landscape, the school emerges as a major site of professional–maternal conflict over a child's right to be included in non-segregating spaces (see Malacrida 2003, 249).

## **Stigmatising Autism Spectrum Disorder**

In his classic book *Stigma: Notes on the Management of Spoiled Identity*, Erving Goffman (1963/1986) made a compelling argument regarding the salience of stigma in social life. When thinking about mothers' stories of informal exclusion, Goffman's framework, and that of other authors who have extended his ideas around disability and stigma, remains productive. From the perspective of some education professionals, it is clear that autism is a deeply discrediting attribute. In encounters with these professionals, mothers, who advocate on behalf of their young offspring, are stigmatised, along with their sons and daughters identified as being on the autism spectrum. It is these 'dynamics of shameful differentness' (Goffman 1963/1986, 140) and their role in policing the boundaries of educational exclusion that I examine here.

Two concepts within the literature on stigma and disability are relevant to my immediate purposes. The first is a distinction between enacted and felt (or perceived) stigma. Enacted stigma refers to episodes of discrimination experienced by stigmatised individuals. Felt stigma refers to the anticipatory fear of enacted stigma and to feelings of shame associated with being stigmatised (Gray 1993, 106; Jacoby 1994, 270; Scambler 2004, 33). The second concept relevant to this analysis is that of 'courtesy' stigma. Goffman (1963/1986, 30) argued that those who are related to stigmatised individuals are also stigmatised because the structural connection



between these two people ‘leads the wider society to treat both individuals in some respects as one’. The notion that parents of children with a disability are subject to courtesy stigma has been examined by a number of authors (Birenbaum 1970; Farrugia 2009; Gray 1993, 2002; Green 2003; Green et al. 2005; Voysey 1972). In the Australian context, David Gray (1993, 2002) has contributed to the study of courtesy stigma amongst parents of children identified with autism. He reports that mothers usually feel more stigmatised than fathers, in part because they ‘take greater responsibility for the public presentation of the family’ (Gray 1993, 114) in fulfilling ‘the traditional role of primary caregiver’ (Gray 2002, 743).

A number of commentators have argued that the link between stigma and disability is weakening over time. This argument tends to take two forms. One is that, as the years pass, parents generally become increasingly resistant to efforts to stigmatise either themselves or their children. The other is that contemporary ideologies of disability as valued difference have effectively overturned negative attitudes towards disability, including autism.

Gray (1993, 117–118), for example, states that parents become less sensitive to the reactions of others over time, developing a growing sense of ‘emotional detachment’. Further, he speculates that an increasing recognition of the genetic causation of autism has helped to reduce stigma, as parents are no longer thought of as responsible for their child’s behaviour (Gray 2002, 746). Sarah Ryan (2008) gives this argument a more contemporary shape by positing mothers of children with disabilities as increasingly resistant to, and distant from, the demands of social conventions. Ryan even optimistically contends that the notions of ‘spoiled identities’ or ‘degraded status’ deployed in classic sociological works on disability and stigma may have outlived their relevance.

Ryan’s optimistic stance was prefigured in the work of anthropologist Joan Susman (1994, 15 and 17), who ventured that the disability rights movement led both to resistance to stigma imputations and to the weakening of the force of such imputations as new ways of thinking about people with disabilities as members of a minority group gained sway. David Farrugia (2009), in particular, has developed this line of thinking in relation to the experiences of parents of children identified with autism in Australia. At the conclusion of this article, I will return to these hope-filled readings regarding the erosion of disability stigma in the light of the material I present on mothers of children diagnosed with autism as they negotiate primary school entry.

Commentators often take interactionist theories of stigma and disability to task for failing to be sufficiently political (Farrugia 2009, 1012 and 1014; Scambler 2004). Disability studies scholars have consistently emphasised the need to focus on the ways that power shapes the distribution of stigma and on efforts to contest these processes (Scambler 2004, 35). While acknowledging the validity of these concerns, my own reading of Goffman's writings on stigma, as a performative process staged during poignant encounters between 'normals' and stigmatised, is that it offers us a powerful way to think through some of the ways in which autism is reproduced as a disabling category in everyday interactions, and of the profound effects this has on the lives of children identified as being 'on the spectrum' and their families.

In the following, I take as my grounding the observation that 'it takes power to stigmatize' (Link and Phelan 2001, 375), that stigmatisation reinforces subordination and that we need to embed processes of stigmatisation within larger political issues. By asking mothers what actually happens when they attempt to enrol their children diagnosed with autism in primary school, and by situating those 'happenings' as potentially stigmatising processes, we gain valuable empirical insights into both the mechanisms of informal school exclusion and the range of responses, uncertain, creative, resistant and despairing, to these anxiety-ridden encounters (see Malacrida 2003, 251).

## **Studying Stigma**

The research presented here is part of a broader study entitled 'Maternal Transitions: When Children with Autism Start Primary School'. The design of this doctoral research is longitudinal, with up to three interviews being conducted with each participant over a three-year period. Purposive sampling was used to allow access to mothers whose children were experiencing various levels of school inclusion in special schools, support classes and regular classes. Participants were recruited through early intervention providers and relevant parent support groups. The material used in this article derives from the first interview, conducted in 2009/ 10 with 22 mothers of children diagnosed with autism who were about to start their first year of formal education.

The children were between four and six years of age and represented the full range of diagnoses across the autism spectrum, including autistic disorder, Asperger's disorder and pervasive developmental disorder not otherwise specified. Nine of the 22 children had an

additional diagnosis of intellectual disability. Semi- structured interviews were undertaken, usually in the participant's home. Topics discussed included experiences of diagnosis, early intervention, and processes of school placement. Interviews lasted from 60 to 90 minutes. Each was recorded and transcribed in full.

Working within the broad qualitative methodological framework of narrative analysis, I thematically interpreted this interview data (see Riessman 2008). From the transcripts, I constructed a synopsis of each interview and a list, open to continuous revision, of major themes occurring across interviews. Having noted the frequent occurrence of stories (bounded segments of interview text) of school exclusion and both enacted and felt stigma, I then re-read each interview that dealt with these issues, extracting and analysing this narrative material. Pseudonyms are used throughout for participants, their children and the schools and many of the service providers they refer to. Other minor details have been altered in an effort to protect the anonymity of participants.

My aim throughout was to encourage mothers to give their own accounts of experiences with professionals. All of these women were aware that I, also, have a child diagnosed with autism. These stories would undoubtedly have been told very differently if I had been identified as a service or education gatekeeper. As another mother of a child diagnosed with autism, I was assumed to have knowledge of the social and emotional world families inhabit following their child's diagnosis and to be 'on their side' (see Barnes 2006, 171; Miller 2005, 67–68). The conversational nature of the interview frequently yielded lengthy accounts of significant events and maternal negotiations of the complex professional world they, of necessity, encounter once their child is identified as being on the autism spectrum.

Amongst the 22 women I interviewed, 10 explicitly reported instances of enacted or perceived stigma in relation to school entry. Nearly all of these narratives were stories of exclusion, or attempted exclusion, of their children from regular classes. Some of the encounters involved devaluing comments that were felt to be discriminatory, but the effects were relatively minor. Others involved actions that were perceived as deeply threatening to the welfare of a woman's child and, sometimes, to herself. As Gray (2002, 747) correctly observes, so-called 'mainstream' settings increase the possibilities of conflict between mothers and education authorities, partly because they also increase the likelihood of rejection. Stigmatising responses were reported across all sectors of the primary school education system in Sydney – Independent, Catholic and government. While some of these mothers were

explicitly struggling for the social inclusion of their children, others had no choice but to send their child to a regular classroom.

### **Education, Autism and Inclusion/Exclusion in New South Wales**

In Australia all of the major education providers are philosophically committed to inclusion (Bell and Dempsey 2001, 3). A number of legal instruments support the policy shift towards inclusive schooling for students with disabilities in New South Wales (NSW), of which Sydney is the capital city. These include Commonwealth and State anti-discrimination legislation, National Disability Standards for Education 2005 and the NSW Education Act 1990 (NSW Government 2011, 3). These legislative measures make it unlawful to refuse a student admission to a school on the grounds of disability. All students in NSW have the legal right to attend their local government school. Nevertheless, as Roger Slee (1996a, 1996b) has noted, the expectation that students with disabilities are guaranteed a place at their local school is undercut by ‘the clauses of conditionality’, including the notion of finding the ‘most appropriate setting’ for a child and the defence of ‘unjustifiable hardship’ on a school.

The push towards inclusion exists within the context of a firmly established special education system. The NSW Government (2011, 2–3) states that it is ‘committed to maintaining a range of education options for students with a disability or special needs’. The inclusion versus continuum of placements debate is especially heated in regard to autism, as a number of studies suggest that these students may not cope well with the hurly burly of classroom life and do better in highly structured and predictable environments (for example, Iovannone et al. 2003).

Making a decision about where to send a child diagnosed with autism to school in NSW thus occurs within the context of a highly fractured education field. Social justice arguments advocating inclusive schooling do battle with special education arguments advocating expertise and the promise of the partial remediation of deficits (Slee 1996b, 22). When a child is diagnosed with autism and an intellectual disability, parents report that they are strongly pressured to enrol them in a special school or a support class. Lack of resources in regular classes often motivates this ‘choice’, as do dominant ideologies of responsible mothering and disability, which make the decision to enrol a child in a segregated setting seem both more caring and selfless (Lilley 2012). Parents would sometimes prefer a segregated setting for their child but are unable to access one.

In the past decade there has been a sharp increase in the number of school students identified with an autism spectrum disorder (ASD) in NSW (Graham and Sweller 2011). This reflects, in part, the rising prevalence of autism both within Australia and internationally. The increasing identification of these students is tied to funding categories, which result in rising costs. Although students identified with ASD are eligible for funding, there is, in fact, widespread dissatisfaction with the levels of funding and support available for children diagnosed with autism (and other disabilities) in regular classrooms. A NSW Legislative Council Inquiry, held in 2010, heard from scores of teachers that the level of support they are provided with in mainstream classes does not allow them to fulfil their responsibility to meet the learning needs of students with disabilities. Parents reiterated this view. This Inquiry found that the growth in demand for special education places was not only driven by an increase in the identification of students with disability. It is also a reflection, it was argued, of the lack of adequate support for students with disabilities in regular classes (NSW Legislative Council 2010, xvi).

The inclusion of students identified with autism in regular classes is, therefore, undercut both by continuing commitment to the provision of segregated education placements and the lack of adequate resources available to make inclusion work. Resourcing inclusivity is a complex issue requiring more than a technical ‘fix’ in the form of, for example, buying more teacher aide (currently referred to in NSW as ‘learning support’) time. School organisation, pedagogy, curriculum and teacher education all require rethinking in the effort to make schools responsive to the range of difference amongst learners in classrooms. Nevertheless, many parents and educators continue to respond to demands for inclusivity and the challenges of diversity in relatively narrow, technical ways (Slee 1993), often substituting older models of integration, which aims to remediate the pupil so that they can fit into established classroom structures and practices, for broader notions of social inclusion emphasising the need for systemic change in the school system in order to cater to the needs and aspirations of diverse learners (see Graham and Spandagou 2011; Runswick-Cole 2011).

This situation is exacerbated by an intensively competitive academic environment, in which schools vie for status and funding based partly on standardised performance indicators, and the accompanying anxiety about league-table performance. As a consequence of this competitive environment, some schools are reluctant to accept students with disabilities as they suspect they will perform poorly in testing and lower the measures of academic performance in

the regular classroom (Aitchison 2006, 31; Slee 1996b, 25). Schools are caught in an invidious situation where government reforms foster competitive and exclusionary educational practices, while simultaneously embracing policies committed to the inclusion of all students with disabilities (Connor and Ferri 2007; see Malacrida 2003, 100). As Runswick-Cole (2011, 116) points out the standards agenda and the inclusion agenda present educators with conflicting demands. Considerable ambiguity and tension therefore exists, for both educators and parents, as school entry is negotiated for children identified with ASD.

### **Costly Encounters: Stereotyping, Information Management and Exposure**

In the back and forth of arguments regarding how best to manage the increasing numbers of students identified with ASDs enrolled in the schooling system, autism functions as a stigmatising category. That stigmatisation is founded on stereotypes. Goffman (1963/1986, 51) describes stigma management as ‘an offshoot of something basic in society, the stereotyping or “profiling” of our normative expectations regarding conduct and character’. Further, he makes the foundational argument that ‘before a difference can matter much it must be conceptualized collectively by the society as a whole’ (1963/1986, 123). Autism, now almost a commonplace disorder within the contemporary developmental landscape, has become a difference that matters.

Two recent Australian doctoral dissertations help us to appreciate this (Foster 2005; Wright 2006). Part of what is illustrated in these studies is the extent to which autism has become a ‘master status’ (see Ryan 2008, 732 and 737; Slee 1993), overriding other identities. When a parent mentions the word ‘autism’, the process of enrolment is often entirely redefined. School gatekeepers respond in a variety of ways, many indicating panic at the potential disorder that may be unleashed on their school by the mythicised student with ASD. There is concern that the student will use up already stretched resources with their learning difficulties and behaviour problems. Perhaps most fundamentally, gatekeepers are uncertain about what a diagnosis of autism implies for a child’s ability to learn and to conform. In this situation, many react defensively with an effort to keep the child out. Parents who are advocating for their child may encounter a mild display of slights, snubs and untactful remarks. Or they may experience a series of hostile and concerted efforts to move them elsewhere in the system.

Mothers are very aware that there are both costs and benefits to either revealing or concealing their child’s diagnosis. The stakes are high. Parents know that the education their

child receives may have a critical impact on both their developmental trajectory and on their sense of being entitled to the range of activities and friendships that other children enjoy. They also know that once their child is known to have a diagnosis of autism, this will constitute a ready-made ‘identity peg’ (Goffman 1963/1986, 57). All aspects of a child’s behaviour and learning difficulties can, and potentially will, be hung on it.

Linda Graham (2007), writing about students diagnosed with attention deficit (hyperactivity) disorder, has argued that schooling, as a series of institutional discourses and practices, is responsible for the psychopathologisation of children who are thought to constitute ‘a problem’. Her focus on the ways in which particular students become ‘a case’, with a file that partly defines how they are thought about and the bureaucratic logic that ‘deals’ with them, can productively be extended to consider the ways in which students identified with autism are managed (and constructed) in a variety of education settings. While it is true that all children are anchored as objects for biography by the education system, children diagnosed with autism have an especially ‘thick’ bureaucratic presence, a presence that invokes the ever-present danger of rendering all of their actions as reducible to expressions of autism.

Nevertheless, most mothers are very direct with school gatekeepers about their child’s diagnosis. This is because they are concerned that their child will require access to additional school resources and, like parents of all children, hope to find a welcoming environment. In this situation, there is little choice regarding disclosure. Mothers generally approach these encounters with extreme anxiety. The following maternal narratives provide insight into these encounters.

Sally, who described her son Todd as having ‘high functioning’ autism, initially received a chilly reception when she broached the subject of his enrolment with a small Independent Christian school, which one of her older children was already attending. She told me, with marked anguish, that they acted as though Todd ‘had a stain on him’. A practicing Christian, Sally was well aware of the biblical cast of her speech, reflecting the discourse of stigma (as a reference to bodily signs designed to expose the spoiled moral status of the bearer [see Goffman 1963/1986, 1]) accusatorily back at her son’s stigmatisers. She felt that the school failed, at this point, to deal with her son ‘as an individual rather than a child that has ...’. Sally was unwilling or unable at this moment in our interview to articulate the word ‘autism’. It was a term that had, literally, caused her too much grief and, she believed, had done a disservice to her child by making him vulnerable to stereotyping. ‘I just feel that Todd is a one off, you know, he’s got his

own little characteristics that only I know about'. This mother's intimate expertise (see Lilley 2011b), based on a recognition of her son's individuality, is represented as more authentic than the stereotypical knowledge of autistic traits and behaviour being deployed by school gatekeepers.

Cathy, who lived in a wealthy area of Sydney, eventually enrolled her son Nicholas in a non-local government school after a series of negative encounters in the Independent sector and with her local government school. A teacher by training, Cathy has 'inside' knowledge of how schools work. She was enraged by the treatment she received, by the educational inadequacies she believed were revealed in conversation and, most particularly, by the stereotyping of students identified with autism as members of a homogeneous category. After visiting a prestigious Independent boys' school during their annual open day, Cathy remarked on the behaviour of the woman conducting the tour:

The other thing she said before I left was, 'Oh, you know, some of them' – them. That's another word that rubs me up the wrong way. 'Some of them', you know, 'you don't know what sets them off, and once they're set off you can't work it out'. 'We had one the other day', like you know, a different race or species.

Cathy's anger was palpable. As the conversation progressed, with Cathy questioning this spokesperson for Toffs College about autism without directly revealing her son's diagnosis, the interaction became increasingly tense. The spokesperson clearly assumed Cathy was considering enrolling a child diagnosed with autism, and went on to tell a number of stories about how the school coped badly with 'these' students. Firstly, she pointed out to Cathy that a student with autism who they had observed during their visit 'wasn't doing anything' while all the children around him were engaged in an art activity. Secondly, she recounted that the school sometimes telephoned mothers to ask them to collect children with autism when their behaviour could not be controlled. The stereotyping alongside the cautionary tales did their intended work of informal exclusion – Cathy stated that her son would attend Toffs College 'over my dead body'.

Other mothers also complained of the overt and tactless response to the disclosure of their child's diagnosis. At times this appears to be a conscious strategy of informal exclusion, the discomfort of the encounter being sufficient to direct a mother elsewhere. Within a culture



of disablism that constructs autism as individual impairment and undesirable difference (see Goodley and Runswick-Cole 2011, 609), school gatekeepers all too often feel anxiously compelled to exclude students with a diagnosis of autism from regular classes.

Nearly all of the maternal narratives I collected regarding informal exclusion related to efforts to enrol children diagnosed with autism in regular classrooms. Natalie's story was the exception. She was interested in a support class option for her son Evan, diagnosed with autistic disorder and described by his mother as 'borderline in some skill areas'. Natalie was attracted to the idea of an autism-specific support class, and visited one in her region. Evan has a tendency to run off and the security of the school grounds was thus an important criterion for her. Natalie described her visit:

West Point is on West Point Road, which is a really busy road, open gates, so not safe, and they had like this fenced little pen where they keep the kids until they're ready to go out in the playground. They said, 'Oh, we can keep him in here until he's ready to go in the playground'. I said: 'No, he's ready to go in the playground. He's already making friends at pre-school. He's social. He needs to be in the playground, not in a cage, and he's never going to be safe in that playground because it's on a busy road'. So that wasn't appropriate.

At one level, the sheer obtrusiveness of physically segregating children identified with autism in the playground offended Natalie. The fence, which separated those who are labelled autistic from their typically developing peers, constituted a stigma symbol, continuously available for perception (Goffman 1963/1986, 101), degrading those forced to play within its confined boundaries. But the fence also made no sense in terms of encouraging the social capacities of these children and helping their classmates to develop the skills to help them to learn to play. Instead of facilitating peer interaction, it blocked it. The fence literally constructed a landscape of exclusion. Evan was eventually enrolled in his local government school after Natalie made a successful application for funding for new fencing around the perimeter of the entire grounds.

### **Strategies and Consequences**

At least four of the mothers I interviewed were discouraged from enrolling their child in regular classes in the Catholic and Independent education sectors on the grounds that the

school chosen would not be able to offer appropriate assistance. Kerry's eldest daughter attended a Catholic school. She attempted to enrol her son, Toby, in the same setting. She told me that she talked with the principal a few months earlier, when Toby still did not have an official diagnosis. Kerry described the encounter:

I gave her what the suspected diagnosis was. I let her know what Toby's capabilities are and that he's just like any other child except for the fact that he can't do one on one things by himself. He would not have destructed [sic] any class. And she said, 'We don't have the facilities available to help him excel'. She didn't say 'no' to the school; she said: 'We don't have the facilities available to help him excel. I personally think that if this was my child, I would be going to a public school, I wouldn't even waste my time here'. ... They even told me if I wanted to enrol Toby in the school and he had any extra needs, speech pathology or anything extra, I'd have to pay for it.

Kerry's story is a succinct summary of two very common strategies of informal school exclusion. The first strategy is to appeal to mothers' deep concern for 'the good of the child' via the argument that the chosen school has inadequate resources and that the child would be better off elsewhere. The second strategy is to suggest sending the child to another school, often in a different sector. In this way the school gatekeeper attempts to do a perceived good service for the entire sector of which they are a part, and to remove 'the problem' of the mother and child as administratively far away from them as possible. In this case, Kerry is directed away from the Catholic sector and to the government sector.

If we turn our attention to the Independent sector, we find similar strategies of exclusion at work. Gaby's son Lance was diagnosed with Asperger's syndrome a little prior to school entry. He has significant behavioural issues. Gaby's older son attends a small Independent community school, Gumnuts, situated in a bushland setting. Lance was enrolled in their 'feeder' preschool. Gaby explained that Gumnuts 'never actually said they wouldn't take him, but they suggested strongly that I look at some other places'. She added: 'So they haven't actually said no. But they have, yeah. They feel that they can't help him as much as he needs'.

The strategy of informally excluding by directing mothers to a different school or different sector is illustrated by Hannah, who was thinking about enrolling her son Paul, diagnosed with autistic disorder and a moderate intellectual disability, in a regular classroom. She

attended the open day of a nearby infant school and thought that the small size and nurturing environment of this school might be a good fit for her son. When she telephoned them, however, she was immediately told to approach her local school, which would be legally obliged to accept Paul's enrolment.

The narratives offered to this point direct our attention to a range of exclusionary strategies in the arsenal of stigmatising practices – stereotyping, an appeal to inadequate resources and doing what is best for a child, directing towards another school or another part of the education sector – that can be considered informal. On occasion, however, mothers experience forms of exclusion at the point of enrolment of a child diagnosed with autism that worry the sometimes fine line between the informal and the formal, and, indeed, appear to be a contravention of existing legislative measures aimed to protect a students' right to enrol in a non-segregated setting, particularly in their local government school. It is time to tell Hope's story.

Hope was advised by her son's paediatrician and preschool teacher that he would be 'suited' for a 'mainstream' school. Her local government school is 100 metres up the road. Hope approached the school early in the year prior to her son's enrolment. She mentioned at her first encounter with the Acting Principal that Mark was a 'special needs' child. Hope gave the following account of the ensuing attempts to exclude her son from attending his local public school:

She said straight up to me, 'No, we don't take special needs children'. I said, 'But you haven't seen my child; you haven't asked what the special need is'. She said, 'No, we don't do that'. She said, 'Take him up to the other public school'. I thought, that's a bit harsh. I rang up my friend who's a teacher at the other local school and I said, 'What's the deal?' She said, 'We've been inundated with special needs kids because all the other schools are knocking them back'. I thought, hang on I can't get knocked back, it's my public school, I can't get knocked back. ... I was just dumbfounded that they can just say 'no' without even looking at the child or even asking. Just a straight out 'no'.

Although Hope did not want to cause trouble and was afraid of further alienating the Acting Principal, her sense of social justice led her back through the school gates. Again, Hope had a meeting with the Acting Principal:

When I began I said, ‘I don’t agree with what’s been said here’. I said, ‘I would like my child to come to this school’. She was saying, ‘No, we’re not having them because it will bring our score down in the school’. And that’s when I got really angry. I said, ‘How dare you! You don’t even know my son. He might bring the score up for you. How do you know he’s going to bring the score down?’ Then I still put my enrolment forms in and just left it.

During the open day formal presentation, Hope tried to ask a number of questions. Each time she raised her hand, she was ignored. Eventually she relayed her questions to the mother next to her, who asked them on Hope’s behalf. Only then would the Acting Principal reply. Hope summed up these stigmatising strategies of attempted refusal, and treatment as a non-person, saying: ‘It’s just been a nightmare; it’s an absolute nightmare’.

Mothers, as we have seen, respond in a variety of ways to these experiences of school exclusion. Their narratives demonstrate the ongoing challenges of negotiating school entry for children diagnosed with autism and the extent to which mothers, and their children, are stigmatised in the course of these processes. Some, like Hope, speak out and raise their resilient hands. Others eventually acquiesce to the demand that their child attend a support class or a special school, making do within a conventional social order that encourages mothers to use segregated educational facilities. The notion that they are ‘co-opted’ as ‘willing participants’ in their child’s ‘estrangement from the mainstream’ (Slee 1994, 159) only tells part of the story. This participation is secured by appeals to maternal ‘reasonableness’ and, as we have seen, the deployment of a range of stigmatising strategies. Ambivalence and suffering may go hand in hand with willing participation. Mothers’ actions are often affectively ambivalent, full of a sense of internal contradiction and difficulty.

## **Conclusion**

At the start of this article, I mentioned that 10 of 22 mothers of children diagnosed with autism interviewed reported stigmatising practices and efforts to exclude their sons or daughters at the point of primary school entry. Seven of these 10 narratives were detailed and lengthy accounts of informal exclusion. Some of the mothers who experienced overt stigma and exclusion in some schools went on to report successful processes of enrolment and school entry elsewhere.

Overall, however, the data presented here give a disturbing picture of the pervasive stigmatisation of children diagnosed with autism and their mothers, as well as a systemic failure of all sectors of the education system in NSW to meet the promises of stated policies of school inclusion. In these maternal narratives of school exclusion we see that mothers, while often resilient and resistant, are also actively pushed around by school gatekeepers who are often intent on keeping out students identified with autism.

Some parents of children diagnosed with autism have a strong public profile as advocates and political lobbyists (Eyal et al. 2010; Lilley 2011a). Discussion of mothers who fit this profile forms a welcome counterbalance to the common tendency to associate parenting/caring for children diagnosed with disabilities with disempowerment (Barnes 2006, 158). In writing about school exclusion and stigmatising practices, it is not my intention to suggest that mothers are passive and powerless. Indeed, the repetition of stigmatising practices directed towards people diagnosed with autism and their families can be a potent breeding ground for disability politicisation. However, the agency exercised by women in this study needs to be placed within the context of a powerful education system that continues to fail in the delivery of inclusion, frequently relying on stigmatisation and accompanying moral discourses of appropriate mothering through sensible school ‘choices’ (Lilley 2012) to buttress ongoing projects of social exclusion. Arguments that autism is no longer a degraded status, or that the stigmatising effects of the diagnosis have weakened, are not supported by the maternal narratives of school exclusion analysed here.

Critical disability studies has tended to dismiss Goffman’s approach to stigma as inherently apolitical. I argue, however, that studying stigma via a narrative approach can be one potent way of exposing the mundane processes of disablism that are reproduced in the everyday relationships between people. School exclusion is an embedded part of wider circulating discriminatory practices and ideologies. Stigmatising responses on the part of school gatekeepers cannot be dismissed as the ignorant actions of a few misguided administrators and educators. The stories told by mothers indicate a broad systemic intolerance for students perceived to be different and potentially disruptive (see Goodley and Runswick-Cole 2011; Runswick-Cole 2011). Revealing and exploring this stigmatisation provides insight into the pervasive blocks and barriers to inclusive education that continue to be experienced by students identified as being on the autism spectrum and their families.

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## **Chapter 5**

### **Publication #3**

#### **Crying in the Park: Autism Stigma, School Entry and Maternal Subjectivity**

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## **Crying in the Park: Autism Stigma, School Entry and Maternal Subjectivity**

In this article I focus on the experiences of mothers of children diagnosed with autism as they respond to, and are shaped by, encounters with stigmatising practices at primary school entry. Analysing narratives recorded during interviews with 22 mothers of children diagnosed with autism in Sydney, Australia, I argue that Erving Goffman's theorising around 'courtesy stigma' is inadequate to the task of understanding the felt experiences of these women. I propose the notion of 'attachment stigma', which more readily does the double work of referring to both the intersubjective mother/child relationship, often intensified and prolonged due to disability, and the role of mothering ideologies in shaping stigmatising responses. Mothers' school exclusion narratives point to the salience of experiences of stigmatisation in the lives of families of children with autism, and to the continuing force of gendered moral rationalities underpinned by punishing notions of 'good' and 'bad' mothering.

Cathy sits slumped on the park bench. Her head is turned in the direction of her two-year-old daughter, playing contentedly on the swings a few metres away. 'Mummy, watch this!' Jessica calls out, gleeful as her body moves with increasing velocity, the warm sensation of the summer breeze and of her mother's nearby presence lifting her spirits. Tears are coursing down Cathy's cheeks. Mother and daughter have just been to their local primary school. Cathy was enquiring about enrolling her son, Alexander. He turns six next year, and is legally required to start school. Alexander has been diagnosed as falling within the autism spectrum. The Assistant Principal who fielded Cathy's enquiries responded with alarm to the news that Alexander is 'on the spectrum'. She leaned across her desk, fixed Cathy with a look located somewhere between pity and firmness, and asked: 'Is he aggressive?' Cathy had been to so many schools that year. She had made enquiries at Catholic schools and at Independent single-sex colleges. She wasn't convinced any of them would be able to give her son the support he needed to thrive. She did not feel welcome anywhere. The Assistant Principal and her knee-jerk reaction to the word 'autism' felt like the final straw. Cathy wanted to go home and curl up and disappear. But she had promised her daughter a trip to the park. She was already worried that Alexander's needs compromised her relationship with Jessica. Duty and grim determination took her to the park bench, but she couldn't fight back the tears. Her daughter, seemingly oblivious, swung higher and higher.

## Researching Mothers

This vignette is based on the narrative of a mother who was in the process of enrolling her child, diagnosed with autism, in his first year of formal schooling in Sydney, Australia. In 2009/2010 I interviewed 21 other mothers of children on the autism spectrum who were also enrolling them in school for the first time. Some experienced enacted stigma, in the form of stereotyping and blatant strategies of informal school exclusion. Mothers who are advocating for their child may encounter a mild display of slights and untactful remarks or they may experience a series of concerted efforts to move them elsewhere in the system (Lilley 2013). Fearing this response, some act accordingly, softening their demands, and lowering their educational expectations. A few of these women accepted a segregated placement for their child, in a support class or ‘special school’ when they had initially sought an inclusive setting. Others exited the formal education system. All grappled with the emotional aftershock, as they morally evaluated the behaviour of school gatekeepers, trying to understand what these discriminatory practices meant for themselves, for their children, and for the kind of society we live in.

The study on which this article is based is a qualitative, longitudinal interview project. Most of the participating mothers (22 in the first year, 21 in the second year and 19 in the third year), accessed through early intervention providers and parent support networks, were interviewed three times over the course of three years. While all of the transcripts (62) have informed this article, I focus mainly on material from the first interview, when the children of these mothers were enrolling in primary school for the first time. The interviews were structured around a number of topics (including diagnosis, early intervention and processes of school ‘choice’) but my approach was very much to allow women to follow lines of thought and feeling that were, at that moment, compelling to them.

Most of the women knew that I, too, am the mother of a child diagnosed with autism. Because my son is a few years older than their children, some, even while I tried to avoid this role, sought advice from me. All treated me as an ‘insider’ who, due to my own positioning and/or my openness to following their preferred links in the conversation, understood something of their situation; certainly my interest in their experience with professionals (such as paediatricians, therapists and educators) marked me as someone who would listen sympathetically to their concerns and their stories.

Amongst the 22 women interviewed, 10 reported instances of enacted or perceived stigma in relation to school entry. Nearly all of these narratives were stories of exclusion, or attempted

exclusion, of children diagnosed with autism from regular classes. In another article (Lilley 2013) I detail these attempted exclusions. Here, using the broad framework of thematic narrative analysis (see Riessman 2008), I focus on mothers' felt experiences of stigma and provide some analytic leverage on this issue through the notion of 'attachment stigma'.

Across a number of indicators these women are a diverse group. The mothers ranged in age from 29 to 48, and in educational level from secondary school 'dropouts' to postgraduate degree holders. Most participants identified as Anglo-Australian but the sample included three mothers of Italian background, one Vietnamese, one Lebanese and one white South African. Four of these women disclosed various psychiatric diagnoses (including clinical depression, schizophrenia, and bipolar disorder), of either themselves or their child's father, to me.<sup>3</sup>

I conceive of this research as an ethnographic project, in the sense outlined by Sherry Ortner (1995) – an effort to understand a life world using the self as the instrument of knowing, and to produce 'thick' understanding through attention to texture and detail. Here I contribute to that ethnographic 'thickness' by focusing on maternal subjectivity, on the 'intentions, desires, fears, projects' (Ortner 1995, p.190) of mothers of children diagnosed with autism as they respond to, and are shaped by, encounters with stigmatising practices at school entry. Such encounters are constitutive in shaping the moral careers of these mothers. This research might be positioned as one response to Olga Solomon's (2010) call for further 'examination of how institutionalized structures of power and processes of representation intersect and shape the lives of individuals with autism and their families', including a careful 'consideration of practices of resistance to these structural forces' (Solomon 2010, p.252).

### **Stigmatising Mothers – From Courtesy to Attachment Stigma**

In his seminal book, *Stigma: Notes on the Management of Spoiled Identity*, sociologist Erving Goffman (1963) defined stigma as arising when an 'attribute' of a person is perceived as 'deeply discrediting' (Goffman 1986[1963], p.3). But, he cautions, 'a language of relationships, not attributes, is really needed' (ibid.). His analysis is focused on 'mixed contacts', that is, those moments when 'stigmatised' and 'normal' are brought together in the same social situation (ibid.,

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<sup>3</sup> The frequency of clinical depression in first-degree relatives of children diagnosed with autism is much more common than in the general population. A family history of psychiatric difficulties and diagnoses is often noted in the literature, especially via the construct of the broader autism phenotype or BAP (Piven et. al. 1997; Matson and Williams 2013).

p.12). These are not static categories – one can only be stigmatised or normal as part of a specific dynamic, and that dynamic will alter depending on context. The stigmatised and the normal are, for Goffman, ‘a pervasive two-role social process in which every individual participates in both roles, at least in some connections and in some phases of life’ (ibid., p.138). The ‘dynamics of shameful differentness’ that arise in stigmatising encounters are a general feature of social life (ibid., p.140).

Stigma not only affects the person who is perceived to have a stigmatising characteristic; it also spreads to those others with whom he or she associates (‘the wise’).<sup>4</sup> Wise individuals, that is those who are intimate with and privy to the daily lives and social worlds of those who are stigmatised, are themselves stigmatised through this connection. Goffman’s concept points to a social structural relationship, which leads others to treat two individuals as, in some respects, one (ibid., p.30). This conflation, whereby someone who associates with a stigmatised person is thereby stigmatised, is referred to as ‘courtesy’ stigma.

As every anthropologist knows, kinship relations carry a suite of obligations and expectations that are particular to each socio-cultural formation. In contemporary Australia, despite decades of feminist and gay challenges to conservative definitions of the family, the expectation still largely holds that mothers will look after their small children. In this sense, ideologies of mothering contribute to the perception that mother and child are a single unit, and the potential stigmatisation of mothers that flows from that. What I am broadly gesturing to here is that if we unpack Goffman’s notion of courtesy stigma, as produced by any social structural relation, and apply it specifically to mothers, we find that the kinship identity that ties mothers to their children is inflected by broader cultural forms of gender ideology and, some would argue, gender subordination tied up with the ethics of dependency and care.

In the following I draw on Graham Scambler and Anthony Hopkins’ (1986) distinction between ‘felt’ and ‘enacted’ stigma, focusing my analysis largely on the former. Stigma is defined as enacted when individuals are discriminated against or lose status due to their negatively evaluated differences. Felt stigma refers to the shame associated with negatively evaluated difference and the fear of encountering enacted stigma. Although the two modes of stigma often reinforce one another in the activities of daily life, the distinction has been useful in

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<sup>4</sup> This use of the term ‘the wise’ derived from an expression current in the 1950s amongst the gay community. The ‘wise’ were heterosexuals who were privy to, and sympathetic with, ‘the secret life’ of homosexuals, thereby gaining courtesy membership of this group (Goffman 1986[1963], 28).



the sociology of chronic illness (Jacoby 1994; Scambler 2004; Green et. al. 2005) and helps us to comprehend the experience of mothers of children diagnosed with autism (see Gray 1993, 2002).

Arlie Hochschild's (1979) writing on 'emotion management', a term she uses synonymously with 'emotion work' and 'deep acting', has helped me to engage with the narratives of stigmatised mothers. Hochschild explicitly leads us away from Goffman's interest in the management of outer impressions. Her 'interactive account' leads us, instead, to the somewhat murky arena of 'feeling rules', to 'how people try to feel, not, as for Goffman, how people try to appear to feel' (Hochschild 1979, p.560). The efforts of social actors to make their feelings 'gel' with social expectations and demands constitute, for Hochschild, the 'underside' of ideology (ibid., p.557).

For many of the mothers I interviewed, their lives are played out on a stage set with barriers and discouragements, slights and injuries, which confound their efforts and exhaust them. Not only do they attempt to manage the strain of social encounters (see Susman 1994, p.18; Ryan 2010, p.871), they also need to manage their own emotions (see Green 2003, p.1367; Ryan 2010, p.873) as they try to behave in ways that allow them to negotiate public expectations around maternity and disability. These expectations exist in both the seemingly positive form of the endlessly good and selfless mother and in the negative form of the bad mother, either responsible for, or contributing to, her child's difficulties.

Wendy Hollway's (2006) work on gender and the ethics of care has also been important in framing my thoughts. Hollway offers a psycho-social analysis of the relational features of self that underpin care. Using John Bowlby's (1969) attachment theory, which argues the foundational importance of the relationship between babies and primary carers, as a springboard, Hollway sees maternal subjectivity, and the ethics of care that ideally flow from it, as situated in 'the reality of the woman's primary responsibility for another life' (Hollway 2006, p.73). She writes:

The new mother might experience the period after birth as being continuous with before, in the sense that she still feels physically joined to her baby, not only through feeding, but through feeling its states registered in her own body and knowing them there (ibid.).

The ability to imaginatively identify with another, which underpins care relationships, is forged in mother-infant attachment and the capacities of mothers are 'born out of this dialectic' (ibid.,

p.20). In this sense, a mother and child are not two autonomous rational individuals. They are joined, through the temporal demands of dependency (feeding, toileting, washing and so on) and through the imaginative work of maternal empathy. We are dealing with intersubjectivity.

In recognition of the intersubjectivity fostered by dependence, and of the dominance of ideologies of the responsible/culpable maternal, I suggest that attachment stigma is a more apt term than 'courtesy' stigma when analysing the stigmatisation of mothers. This is partly because the connotations of polite formality inhering in the term 'courtesy' do little to capture the visceral pain experienced by stigmatised mothers. It is also because mothers cannot simply be included in the larger category of the 'wise' without doing an injustice to the particularity of the dynamics between mother and child, and to the ways in which that impacts on maternal subjectivity. Indeed we do ourselves a discourtesy if we think of mothers as just part of some general list of those who might be in a structural relationship to a child and thereby potentially subject to courtesy stigma.

Mothers both feel and are felt to be different from a range of helpers and workers who may attend to the needs of children. The quality of their relationship is more intimate and the extent of their responsibility is greater. In saying this I allow for the possibility that, in particular circumstances, fathers and other carers may experience attachment stigma, especially when they are the primary nurturer of a child. However, we need to recognise that, firstly, the weight of societal expectation for socialisation continues to fall on mothers and, secondly, that the psychological identification with infants and young children, informed by culturally mediated biological processes including pregnancy and breastfeeding, is usually most strongly achieved by mothers.

Attachment stigma does a better job than courtesy stigma of helping us to theorise this doubling. On the one hand, a mother feels intensely attached to her child, and this sense of intersubjectivity leaves her especially vulnerable to the stigmatising actions of others towards her son or daughter. On the other hand, ideologies of mothering posit her as largely responsible for not only the wellbeing but also the inner psychological makeup of her child. While both parents may be thought of as contributing to the being of the child, nowadays generally construed in genetic terms, mothers are usually held primarily accountable for their children.

As a concept, attachment stigma is applicable to all cases where mothers are stigmatised by others because of widely circulating ideologies of maternal responsibility/culpability or, due to the dynamics of interdependence, feel the stigmatisation directed towards their child as their

own. Where a child's dependency is prolonged, as with disability or chronic illness, the conditions for attachment stigma flourish.

### **Theorising Prolonged Dependency: Developmental Disability and Attachment Stigma**

A number of authors have examined the notion that parents of children with a disability are especially subject to courtesy stigma (e.g. Birenbaum 1970; Voysey 1972; Green 2003; Green et al. 2005; Farrugia 2009). Others have been specifically interested in the dynamics of maternal stigmatisation. More than forty years ago, Arnold Birenbaum (1970), in a study of the adaptations of mothers of 'mentally retarded' children, argued that such mothers inevitably acquired a courtesy stigma (a situationally induced social construct), which results in 'an alteration of the mother's relation to the community' (Birenbaum 1970, p.205). At the time Birenbaum was writing, 'the conventional social order' demanded that all of these children, deemed in contemporary terms to have a moderate intellectual disability, receive a segregated education or remain at home. In this situation, mothers were unable to fully retain their 'former social identity'. Birenbaum thus directly linked the segregation of children with disabilities to the stigmatising experiences of mothers.

In Australia, David Gray (1993, 2002) has studied courtesy stigma amongst parents of children diagnosed with autism. He argues that mothers usually feel more stigmatised than fathers, in part because they 'take greater responsibility for the public presentation of the family' (Gray 1993, p.114) in fulfilling 'the traditional role of primary caregiver' (Gray 2002, p.743). The fact that these mothers often remain at home is not only related to their 'traditional' role; it is a direct outcome of the inadequate provision of supports and services for the developmentally disabled and the consequent structural demand that one parent is constantly available for caregiving, negotiation with services and advocacy (see Lilley 2011a, 2011b, 2014).

More recently, Sara Green's (2003, 2005) work on the experience of courtesy stigma in families of children with disabilities has focused attention on the 'subjective burden' of stigmatisation. Arguing that a stress on the routine work of the caregiving task (or the 'objective burden') has distracted our attention from the 'internal turmoil experienced on a regular basis' (Green 2003, p.1366) as a result of coping with the reactions of others to children with disabilities, Green concludes that 'the degree of stigma expected by mothers has an impact on emotional and social outcomes for themselves and their children' (ibid., p.1371). In doing so she underlines the effects of a range of emotions that both flow from stigmatisation and come,

through the force of taught expectation, to structure responses to interactions with those outside the immediate family – ‘embarrassment, guilt, shame, resentment, entrapment, worry’ (ibid., p.1364).

There is great heterogeneity amongst individuals diagnosed with autism. This heterogeneity is commonly referenced by use of the term ‘autism spectrum’, a concept first fully articulated in the influential research of psychiatrist, and mother of an autistic child, Lorna Wing (1996). Indeed, since 2013 Autism Spectrum Disorder (ASD)<sup>5</sup> is the name of the relevant diagnosis authorised by the American Psychiatric Association in the DSM-V. Some who meet the criteria for this diagnosis are relatively high functioning with complex speech and areas of intellectual attainment and interest. Others have an intellectual disability and more limited capacities. There are no established biomarkers for ASD (Matson and Williams 2013) – in order to be diagnosed individuals must demonstrate, at varying levels, persistent deficits in social communication/interaction as well as restricted and repetitive behaviors (Hyman 2013). These impairments generally result in prolonged dependency. This dependency fosters ongoing heightened maternal care and protection, which, in turn, provides the conditions for attachment stigma to flourish.

A detour into the history of psychoanalytic theorising assists in fleshing out this concept. In 1956 psychiatrist and psychoanalyst Donald Winnicott (1958) proposed the notion of ‘primary maternal preoccupation’ as part of his influential theorising on maternal contributions to the development of healthy ego maturity through the provision of a ‘good enough’ environment for the infant and young child (Winnicott 1984[1958], pp.300-305). For Winnicott, the idea of a symbiotic relationship between mother and infant did not go far enough, only indicating a necessary physical interdependence. Searching for a way to describe the identification (conscious and unconscious) between mother and infant, Winnicott offered primary maternal preoccupation as both a description and an explanation of a psychological condition of maternal heightened sensitivity towards her child in the early stages of life. He saw this as a ‘normal illness’,

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<sup>5</sup> Some researchers prefer the term autism spectrum ‘condition’ to autism spectrum ‘disorder’. The use of ‘condition’ is intended as an acknowledgment of the claims of the burgeoning neurodiversity movement, which casts autism as a form of difference rather than a disability (Savarese 2010, 273). While I acknowledge the importance of this political shift, and its capacity to resituate assumptions and presumptions about those diagnosed with ASD, I choose to retain the term ‘disorder’. Once a diagnosis is made, family lives become framed by medicalised understandings of autism and parents grieve intensely over the impairments that have led to diagnosis in the first place and their consequences for the future (Lilley 2011b). Following diagnosis, mothers generally perceive both their child, and their family’s lives, as disordered.

experienced near the end of a pregnancy and over the first few weeks of a baby's birth, which provides a healthy setting for developmental tendencies to start unfolding. A mother, he argued, must then recover from this phase of deep sensitisation in which 'she can feel herself into her infant's place, and so meet the infant's needs' (ibid., p.304) in order to allow her baby to develop as an independent being.

While Winnicott suggested that the persistence of this deep sensitisation to the needs of another is psychologically unhealthy, many feminist theorists have challenged the model of an autonomous self that underpins this model of ego development. Especially in situations of ongoing dependency, permeable ego boundaries facilitate caretaking and intimate relations. Moral philosopher Eva Kittay (1999), for example, drawing on her own experience of her disabled daughter's ongoing requirement for substantial care, argues for the necessity of a 'transparent self' (Kittay 1999, p.51) through whom the needs of another are discerned. Theoretically this mirroring of need might ideally occur with any dependency worker. However, mothers provide the paradigmatic example of the capacity to defer their own desires in order to meet the needs of a dependent.

More recently Susan Kelly (2005) has provided an account of the co-constitution of parenting identity and childhood impairment that assists us to think about the specificities of maternal subjectivity. She alerts us to the importance of experiential knowledge in constructing maternal subjectivity; to the intercorporeal and intersubjective mutualities of dependency relationships that render the task of rearing a child with disability both potentially rewarding and often exhausting. Because these children require ongoing assistance with many of the activities of daily life, and because mothers are required to assertively advocate on their behalf in a range of social arenas, including education placement, the deep identification of a mother with her child that with typically developing children may be expected to dissipate over time, can remain at a level of intensity more usually associated with the early childhood years.

Adopting Winnicott's terms, the period of primary maternal preoccupation is lengthened when a child remains dependent. Feminist theorists, like Kittay and Kelly, allow us to see that this necessarily ongoing primary maternal preoccupation is not pathological; rather, it is the condition and the ground of 'good enough' care. It is also, I contend, the basis for intensified attachment stigma. Much of the existing literature on courtesy stigma points us in this direction but slightly misses the maternal mark in continuing to classify mothers as simply part of a larger conceptual set of persons structurally tied, through either work or kinship relations, to individuals

with disabilities. My preference for the term attachment stigma over courtesy stigma is intended as a way of acknowledging that the intimacies of caring for a child with a developmental disability involve a prolonged period of primary maternal preoccupation, which results in a particularly intense dynamic of stigma wherein mothers feel that the slights directed against their son and daughter are insults to their selves.

When mothers talk about their care we find frequent references to the hard work of looking after and encouraging these children. Hannah's son is diagnosed with autism and an intellectual disability. I asked her whether she felt it was very different to be the mother of a child with autism than of a typically developing child. Laughing at the absurdity of being questioned about an issue that seemed, to her, so patently obvious, she replied:

Absolutely. Need you ask! Ah, gee, I think that looking after a normal child must be like having a pot plant; you know, you just water them and put them out in the sun every now and again and they just develop. It's amazing. I see normal kids and what they're capable of doing and people are so lucky to have that ... No, it's a completely different experience. Everyday life is different. For me getting Paul from the morning until bedtime, getting through a day, it's a struggle every step of the way, honestly.

Sarah explained some of the difficulties of mothering her son David by comparing him to her typically developing older daughter. She described encounters with David as stilted and as requiring constant maternal work:

Then you got David who all of a sudden is not understanding, 'get that glass', 'get that toy and put it there' and just the simplest things. You can't even explain it. The simplest things that kids learn automatically or you take for granted; everything has to be explained and shown and pointed out and helped. Then you think, *this is work*. Sure there are people with more severe disabilities who've got it even harder, of course, but having a child that has no problems to a child that has additional needs, whatever they may be, you mean you could have ten of, what's the proper word, 'neurotypical'.

Writing at a time when psychodynamic explanations for autism causation were prevalent, Winnicott described the type of mother who produces an autistic child as one who does therapy instead of parenting (Winnicott 1984[1958], p.303). This, he argued, stemmed from an earlier

failure of primary maternal preoccupation. Both Hannah and Sarah make it clear that they continue to be preoccupied and that part of the task of good enough care is to interact with their children in ways that enable understanding and alleviate anxiety. They struggle, together, every step of the way.

### **Autism and Mother Blame**

My use of the term attachment stigma also references the extent to which mothers are held to be culpable for their child's disability, partly through the ongoing transformations of attachment theory as it works its way through the labyrinthine corridors of institutional life, whether in the school or the hospital or the clinic. In other words, mother-blame is the flip side of the profound influence of attachment theory in psychological understandings of child formation, which, in turn, shape practitioner views in diverse contexts involving the professional surveillance of mothering capacities, including early intervention and education.

When children have difficulties that come to the notice of those outside the immediate family, there is a widespread tendency to attribute those problems to maternal failings. Mothers are prime suspects in the course of disordered development, readily charged with 'laying inadequate moral, psychological and emotional foundations for their children' (Malacrida 2003, p.13). In the case of autism, a brief but florid psychoanalytic history laid the blame for this disorder on so-called 'refrigerator mothers' who, with their 'coldness, obsessiveness, and a mechanical type of attention' (Kanner 1949, p.425), created a monstrosity lacking inner self, an 'empty fortress' (Bettelheim 1967), manifested in their children's rigidities, anxieties, withdrawal and repetitive behaviours (see McDonnell 1998, p.225; Solomon 2010, p.247).

Such views have largely passed out of psychiatric favour. Nevertheless, the notion that autism is a disorder of affect, unwittingly contributed to by inadequate mothering, retains currency in some contemporary forms of mother-blame, engaged in by experts and non-experts alike. Borrowing Goffman's felicitous phrasing, we can say that this mother-blame is 'fully entrenched nowhere'; yet it casts a 'kind of shadow on the encounters encountered everywhere in daily living' (Goffman 1986[1963], p.128-9).

Nowadays, the consensus view is that autism is a complex developmental disability involving interactions between genetic and environmental factors. In other words, the official stress has shifted from mother-blame to 'brain-blame' (Ryan and Runswick-Cole 2008, p.200).

Indeed, ASD, with a heritability of 80 per cent, is now reported to be ‘one of the most familial of psychiatric disorders’ (Eapen 2011, p.226).

The emphasis on the strong genetic basis of autism leaves parents in an ambivalent position regarding the issue of responsibility for their child’s disorder. Investigators describe social, cognitive and psychiatric deficits (such as rigidity or hypersensitivity) in the relatives of autistic probands, suggesting that ASD is the core presentation of a broader phenotype shared with parents (Ciaranello and Ciaranello 1995, p.102; Merin et. al. 2007, p.109). When mothers believe that either they or their partner share some autistic traits in common with their diagnosed child, the oscillations between blame and identification can become especially volatile.

I argue that we can better understand the dynamics of maternal stigmatisation through the notion of attachment stigma, which references both the intersubjective relationship between mother and child, especially where there is prolonged dependency, and public ideologies of mothering that render women potentially culpable for their child’s impairments and responsible for ‘fixing’ them (see Lilley 2011a). Given this, mothers are very vulnerable to implied criticism and likely to respond with heartfelt anger and distress to the stigmatising actions of others.

### **Mothers, Autism and Moral Careers**

Mothers of children diagnosed with autism are especially vulnerable to stigmatisation at the point of school entry. As research repeatedly shows, mothers are the main carers of young children and, in particular, of children with disabilities, including autism (e.g. Malacrida 2003; Kingston 2007; Ryan and Runswick-Cole 2008; Landsman 2009; Silverman 2012). Beyond the quotidian concerns with everyday needs, these mothers spend considerable time as advocates with schools, and other agencies, in search of the services and attention their child requires (Lilley 2011a, p.136).

I investigate the stigmatisation of these mothers at the point of primary school entry, taking care to consider both Birenbaum’s observations on the link between segregation and threats to maternal identity, as well as Green’s emphasis on the chronic emotional distress engendered by stigmatising practices. In doing so I make use of Erving Goffman’s notion of ‘moral careers’. He noted that people ‘who have a particular stigma tend to have similar learning experiences regarding their plight, and similar changes in conception of self – a similar “moral career” that is both cause and effect of commitment to a similar sequence of personal adjustments’ (Goffman 1986[1963], p.32).



This observation, penned in the early 1960s, applies with equal force today. Coming from diverse ethnic backgrounds and class locations, mothers of children diagnosed with autism are constituted as a group – as ‘autism Mums’ – by the shared commonality of diagnosis and their subsequent experiences with early intervention, schooling, post-school options and so on (Lilley 2011a, p.151). While all mothers are generally expected to take responsibility for the wellbeing of their children, this medicalisation of the family has especially intense pragmatic and emotional repercussions for those whose children fail to meet the ‘persuasive grip’ of the standardised child (James 2005, pp.102-3). For these women, their sense of belonging to a group also arises from their common experience of grief and marginalisation stemming from caring for children who frequently do not fit the regular progression of expected childhood milestones and achievements (Lilley 2011a, p.153).

Mothers are stigmatised, both as mediators between their children and the various state apparatuses involved in the surveillance of childhood, and as potentially inadequate parents (as purportedly evidenced by their ‘at risk’ children). These processes are especially evident during key times that inculcate children and family members, especially mothers, into stigmatised careers. School entry is one of those key times. As Goffman reminds us, ‘the resulting instabilities in interaction can have a very pervasive effect upon those accorded the stigmatized role’ (Goffman 1986[1963], p.138). In this situation, mothers articulate real fears about what will happen to their children, but also real fears about being seen to be the wrong sort of mother. Such fears reveal a great deal about the ongoing struggles for social inclusion necessitated by the continued pathologisation of children with ASD and their families. They also take us into the contested terrain of mothering and motherhood in contemporary Australian society.

### **Stigmatisation and School Entry**

A number of scholars have argued that the link between disability and stigma is weakening as positive views of disability as valued difference gain ground. My research on the stigmatising responses of educators to mothers and their children identified with autism as they negotiate primary school entry does not support this view. Autism is frequently reproduced as a disabling category in everyday interactions with school gatekeepers, and this stigmatisation has potentially profound effects on families who have a child on the spectrum (Lilley 2013).

The immediate context of these stigmatising encounters is an education system in New South Wales (NSW) wherein all the major providers are officially committed to inclusive

schooling for students with disabilities, including autism. A number of legal instruments support this policy, including Commonwealth and State anti-discrimination legislation, National Disability Standards for Education (2005) and the *NSW Education Act 1990* (NSW Government 2011, p.3). These legislative measures make it unlawful to refuse a student admission to a school on the grounds of disability.

All students in NSW have the legal right to attend their local government school. However, as Roger Slee (1996a, 1996b) has pointed out, the expectation that students with disabilities are guaranteed a place at their local school is undermined by ‘the clauses of conditionality’, including the notion of finding the ‘most appropriate setting’ for a child and the defence of ‘unjustifiable hardship’ on a school. Further, this push towards inclusive schooling exists within the context of a firmly established special education system, which provides both support class and special school placements for children identified with autism. This option is particularly encouraged when students are also diagnosed as having a moderate or severe intellectual disability.

In recent years there has been a steep rise in the number of students diagnosed with ASD. Their inclusion in regular classes continues to be undercut both by continuing commitment to the provision of segregated education placements and the lack of adequate resources available to make inclusion work. Further, Australian schools now compete for status and funding partly on the basis of their students’ performance in standardised national academic testing. In this situation, some schools are reluctant to enrol students whose performance may be below average. Put differently, while the rhetoric of inclusion is well-established at policy level, the extent to which the education system is either able or willing to make adaptations that could conceivably convert the schooling trajectory of its disabled students, now frequently coded as autistic, into a substantive and meaningful experience of participation, remains limited (see Eyal et al. 2010, p.262).

School gatekeepers are concerned about the learning difficulties and behaviour problems that often accompany a diagnosis of autism. Given inadequate resources, they may respond to parental disclosure of a child’s autism with various strategies of exclusion. This was most overtly revealed in the exclusion narrative offered by Hope (see Lilley 2013) who experienced a range of attempts to exclude her son from his local government school. She endured direct coercion to stop her submitting enrolment forms, efforts to embarrass and humiliate herself and her son in front of other families, and studied attempts to ignore her questions at a school open day event.

Ultimately, these strategies were unsuccessful. Hope, who knew her legal entitlements, enrolled her son at his local school. We will return, later, to the issue of how all of this affected Hope, and to the anxieties and desires she marshalled in trying to comprehend the stigmatisation of both herself and her child.

One common strategy of school exclusion is to appeal to a mother's concern for the educational welfare of her child by claiming inadequate resources to properly help the student with autism at the chosen school. The second common strategy, often chronologically following the first, is for a gatekeeper to suggest sending the child to another school, often in a different sector. Although such strategies are widely perceived as 'informal', I argue they amount to forms of structural discrimination against students diagnosed with autism in that these forms of attempted exclusion occur with sufficient frequency to constitute accumulated practices that work to the disadvantage of this group (see Link and Phelan 2001, p.372).

Mothers respond with a variety of tactics to these strategies of school exclusion. They may interpret the behaviour of gatekeepers as stemming from ignorance or professional incapacity. Some become angry; others develop a kind of stoicism, which they believe is effectively required by the difficulties of their situation. Some hope to avoid the possibility of further stigmatising encounters when they decide to place their child in a support class or a special school. As these are segregated settings, it is less likely that mothers will have negative encounters on enrolment. Others avoid further stigmatisation through deciding to opt out of the formal education system, either through non-enrolment or home schooling.

Understanding these maternal tactics within a dichotomous framework of resistance versus non-resistance only serves to impoverish them. The distinction I draw between maternal tactics and the strategies of school gatekeepers derives from Michel de Certeau (1984). He links 'strategies' with institutions and structures of power, while 'tactics' are described as an 'art of the weak', calculated actions limited by the possibilities of the moment that are utilised by individuals as they manoeuvre within environments defined by strategies (de Certeau 1984, pp.37-38). In de Certeau's model possibilities always exist for contesting the social order (created through multiple strategies) through the tactical practices of everyday life.

At the point of enrolment, both school gatekeepers and mothers are caught in frequent gaps between official policy and practice that flourish in the uncertainty created by debates over 'what is educationally best' for children identified with autism, and left to deal with the guilt and ambivalence that these contradictory discourses generate (see Lilley 2012). Mothers' stories

about negotiating school entry are set within a field of struggles, both ethical and material, to obtain a particular sort of education for their child, which is connected to a vision of their potential future. In the process, they try to present themselves as ‘good’ and responsible mothers to an audience whom they imagine are judging their actions and their motivations ‘against some standard of how a parent of an impaired child should act’ (Kelly 2005, p.191).

These narratives, like all forms of autobiography, cannot simply be taken at face value. They are self-conscious reflections on the project of mothering a child identified with autism and, at their most poignant, provide troubling reflections on exclusion and loss. In these instances, transition to primary school may be represented retrospectively as an isolating and incapacitating experience for mothers who, in the process of repeated stigmatising encounters, become what Goffman has termed ‘situation conscious’ (Goffman 1986[1963], p.111). Goffman intended this term as shorthand for a cognitive process that occurs when a stigmatised individual is stimulated, by repeated experience, into ‘becoming a critic of the social scene, an observer of human relations’ (ibid.).

In her analysis of parents of children with chronic illness and disabilities, Margaret Voysey (1972) provides a different take on Goffman’s preoccupations. She argues that where parents are uncertain of their child’s condition or their own competence, ‘they may be highly conscious of alter’s opinion as implied by his treatment of parent and child’ (Voysey 1972, p.82). In turn, the ‘frequent questioning of their actions by themselves and others may increase parents’ awareness of the dynamics of interaction’ (ibid., p.88). This increased awareness may lead to increased mastery over the management of interaction.

Certainly all parents of children diagnosed with autism are ‘uncertain’. Autism is a lifelong developmental disability. It is routinely described as a ‘devastating neurological abnormality’ (Frith 2003, p.1). The children contained within this label vary so widely, and their developmental trajectories may take so many different paths, that ongoing uncertainty about a child’s potential are a constitutive element of diagnosis. In the interests of a realistic appraisal, experts are often keen to tell parents that most adults with ASD are unemployed, friendless and do not live independently (Sigman, Spence and Wang 2006, pp.339-340). In the midst of this lived experience of uncertainty, only the most brash of individuals could avoid a frequent sense of incompetence. Voysey and Goffman together take us towards a particular type of realist comprehension of the situation mothers of children identified with autism find themselves in. The strategising actor is at the heart of their understandings.

While acknowledging the potential social reality of this strategising actor, with their sceptical orientation and calculated management of encounters, in the following I propose we shift our attention to a different dimension of maternal responses to repeated stigmatisation. Hollway perhaps comes closest to what I have in mind when she writes:

Events in the external world are not just mediated by language or discourse but, importantly, by people's states of mind. By this I do not refer to cognitive processes but to "mental states" or "internal worlds" where desire and anxiety act creatively on experience and transform it, so that its relation to reality can never be simply assumed. (Hollway 2006, p.17)

In enacting narratives of school exclusion, mothers sometimes produce accounts that allow partial access to these internal worlds, to the ways in which their desires and their anxieties help to make sense of their experience as they struggle to position themselves as 'good' mothers of beloved children (see Vincent, Ball and Braun 2010, p.128).

### **Maternal Subjectivity and Autism Stigma**

Once again, I assert the partial reality of the rational actor, this time Gallic and martial rather than Anglo and restrained, that de Certeau's model proposes. But this 'subject' is only part of the story, doing little to explicate either the emotional intensity of stigmatising encounters at school entry or the ways in which a maternal self is threatened by strategies of exclusion. Stigma is, as anthropologist Lawrence Yang and colleagues (2007) remind us, 'grievously felt' because it threatens moral standing (Yang et al. 2007, p.1529). They explain: 'In this context, the loss of social standing and weakening of social ties resulting from stigma become inseparable from feelings of overwhelming shame, humiliation and despair' (ibid., p.1532).

Graham Scambler (2004), too, has broached this theme, suggesting that: 'Sociological acknowledgement is required too of a logic of shame that requires/orders/establishes the parameters for relations of stigma' (Scambler 2004, p.40). Ann Jacoby (1994), in a study of the stigmatisation of people with epilepsy, provides perhaps the most direct approach to comprehending the internal turmoil that stigma creates, noting that 'stigma is not solely the outcome of societal devaluations of differentness: in order for stigma to exist, individuals possessing such differentness must also accept this devaluation' (Jacoby 1994, p.269). This succinct formulation successfully elides the issue of how social meanings come to be both

internalised and contested. Nevertheless, the notion that a person might simultaneously accept their devaluation and fight against it provides us with a way of thinking about some of the complexities of maternal subjectivity and autism stigma.

I began this article with a vignette about a mother crying in the park. I want to return to that moment. And this time I want Cathy to tell her own story. We need to recall that she was talking with an Assistant Principal at her local government school about the enrolment of her son Alexander, diagnosed with ASD, in the following year:

When I was in her office, I told her the diagnosis and she said, as soon as I said ASD, she leaned forward and said, ‘Is he aggressive?’ I was furious that that was the first question and the most important question that she needed to know straight away. Not, ‘What is your child’s name?’ or ‘Does your son go to preschool? What sort of interventions has he had?’

I felt really—I went to a park after that, because I had my daughter with me, and again, with the guilt thing. I thought, everything’s taken up by my son. I know it’s not his fault but it takes me away from meeting her needs a lot is how I feel. So I decided, I’d already planned after the school meeting I was going to take her to the park to play on the swings.

I took her to the park and I just cried in the park because I thought, no, I have to take her to the park. But then I sat there, shell-shocked after this woman had treated me this way and treated my son this way, and I was angry and I was really—I was angry that she would have that—angry about her ignorance and insensitivity and laziness as well, and really sad and frightened for my son, thinking, ‘Is this what he is going to be dealing with? These sort of people? Where am I going to go?’

Cathy’s exclusion narrative highlights the extent to which she exerts self-control and restraint during the stigmatising encounter, and the ways in which her emotion management masks the intensity of her anger at the stereotyping of her son as violent. The emotional turbulence created by repeated experiences of school exclusion comes to a head as maternal duty takes her to the playground, and is poignantly mixed with self-blame. Cathy fears that she is an inadequate mother; that her necessary focus on her son makes her unavailable to her typically developing daughter. In Hochschild’s terms, Cathy is desperately ‘conscious of a moment of

“pinch” or discrepancy, between what one does feel and what one wants to feel (which is, in turn, affected by what one thinks one ought to feel in such a situation)’ (Hochschild 1979, p.562). She is exhausted by the emotional demands on her and conjures the distance between her fantasised experience of being a mother and the actual experience of being the mother of two children, both of whom have pressing needs. She responds to stigmatisation, and feelings of immobilisation, of being ‘stuck’ in an impossible place, with a range of, if you like, internal tactics that move rapidly from anger, to self-blame (I am a bad mother), to blame of others (they are a bad educator). She feels isolated and peripheral; there appears to be nowhere to go. The stigma directed towards her son is felt as stigma directed towards her as well (‘then I sat there, shell shocked after this woman had treated me this way and treated my son this way’). Accusations against him are accusations against her. It is not only, as Goffman theorised, that courtesy stigma is generated by a social structural relationship between parent and child, which leads others to treat these two people as one. It is also that the intersubjectivity of mother and child lead Cathy to experience her own self as deeply enmeshed with that of her son.

Part of the reason mothers respond with such intensity to autism stigmatisation is because they are very aware of the full force of common views about autism, which include notions of violence linked to lack of affect, severe learning difficulties, emotional remoteness and so on. Tied up with these stereotypes are frequently expressed notions that parents are not coping well with having a child with autism, that they need professional assistance to ‘manage’ their son or daughter and that there is probably more that they could be doing to help their child – higher expectations, more realistic goals, a firmer hand, a gentler manner, following maternal instincts, taking expert advice, trying another therapy, taking a different approach. And so it goes on. There is a sense of constant surveillance of parenting skills that goes hand in hand with the exposure to specialised agencies and services following diagnosis (early intervention, occupational therapy, speech therapy, special education etc.). Ryan (2010) has argued that disclosing a child’s ‘autistic identity’ effectively replaces ‘the spoiled identities of incompetent parent and badly behaved child’ (Ryan 2010, p.873). Certainly disclosure may help to rework overt expressions of mother-blame. However, my interview data points to the ongoing force of such accusations and their frequent internalisation. Taking minor pronominal liberties with Goffman, I suggest this is partly traceable to the fact that ‘the standards [s]he has incorporated from the wider society equip h[er] to be intimately alive to what others see as h[er] failing’ (Goffman 1986 [1963], p.7).

The unforgiving context in which women mother children diagnosed with autism, the ways in which they continue to be convicted of, and convict themselves, of BAD Mothering (Quiney 2007, p.26) was narratively revealed by a number of interview participants. Earlier we met Hope, who staunchly refused to accept her son's exclusion from their local school. Hope struggled repeatedly against accusations of bad mothering and her own guilt in relation to difficulties with breastfeeding. These tensions surfaced in her affinal relations, especially with her mother-in-law:

My in-laws have no understanding of autism, no matter how hard we try to explain it to them; they've had no understanding. They think he's a naughty little boy and that he needs to be corrected all the time. When I stopped breastfeeding Mark, my mother-in-law was at me constantly that this is the worst thing you can do, stop breastfeeding your child and 'I can't believe you're doing this'. So I got the guilts, not only from myself but from outside, [so] that I was just a mess. I thought this is—and my relationship with my son was a guilt thing, thinking I have to breastfeed you and I have to do this to you and it wasn't working for us.

Hope clearly recognises the force of the crude mother blaming that is so rife in our culture (see Parker 2009). She also provides a succinct sense of the connection between shame and guilt, and the ways in which these emotions sometimes dominate her sense of her relationship with her son. Rozsika Parker (2009), in her theorising on maternal ambivalence, provides assistance in understanding this dynamic. She writes:

Shame, in the context of infantile development, is seen as developing earlier and focusing on failures and weakness of the self, while guilt focuses on the things done. Motherhood is both an identity and a set of behaviours; hence for mothers the two affects act particularly closely in concert. ("I am a bad mother. I am getting it all wrong."). (Parker 2009, unpaginated)

This feeling of 'getting it all wrong', of having 'the guilts', was amplified by Hope in her account of the ways in which she perceives herself as differently mothering her typically developing younger daughter and her older son with high functioning autism:

If I go to a park I can let Amy run and that's fine but with Mark I'm constantly thinking, 'Is he going to lash out at someone that's in his space?' or 'Is he going



have a breakdown and I won't be able to control him?' So it's totally different how I've raised them. I've been more cotton wool with Mark to make sure that he's alright all the time and [I've] let Amy just kind of fend for herself, which sounds awful but that's how it's worked out that Amy is very independent as Mark is very reliant. I think I've made him reliant on me because I have been so worried how people are going to accept him and things like that. ... I think I still feel guilty about not having had enough professional help with him, but I've tried to make the best of my situation that I can.

Hope struggles here with 'the personal impact of powerful moralistic discourses of maternal culpability' (Quiney 2007, p.33), which trade on simultaneous warnings of overprotection and accusations of neglect (Parker 2009).

Mother-blame was a consistent trope in these women's narratives. They bring these experiences of mother-blame to varied stigmatising encounters, both as an attitude they recognise, and are angry about, and, simultaneously, as an accusation they feel may be, in part, true. This is because their reactions to themselves as mothers are forged within these societal discourses of maternal culpability and because the experience of maternal care, and of the intersubjectivity that both shapes and is shaped by that process, urges them on to the seemingly inescapable conclusion that they are responsible for forging the psyche of their son or daughter. The increasingly visible trend to impose absolute responsibility for children's faults or difficulties on mothers has been noted by feminist theorists (see Quiney 2007, p.34). In this sense, the dilemmas of maternal culpability experienced by mothers of children identified with autism are one variant of a wider cultural logic.

Some of the women I spoke to were quite explicit about the links between particular instances of mother-blame and wider societal discourses that are, in part, formed by theorising in the 'psy' disciplines. Kerry told me that medical professionals had consistently told her that there was nothing wrong with her son, that she was being over-demanding because she is a 'high achiever'. Her son was finally diagnosed with autism and an intellectual disability when he was on the brink of school enrolment. Speaking about her sense of social isolation and stigmatisation, she remarked:

My husband's family, which we live in, don't believe in autism. They do not believe that there is anything wrong with Toby. So I don't really have my support

there. My family, they're only limited in what they can do. I tend to stay away from people because I've had—I've already been told one too many times, once again the 'high achiever' comment, that it's my fault that Toby is the way he is. I never spent enough time with him as a child; I don't talk to him enough. It's kind of like, back in the 1940s, they used to call mothers of autistic children 'refrigerator mums'. It's almost going back to that kind of thing again.

Again, we are given a glimpse into familial forms of mother-blame, partly linked to processes of denial. Kerry explicitly draws the listener's attention to the connection between this discourse of maternal culpability and to expert opinions. She links both of these forms of mother-blame to psychoanalytic views, prevalent in the 1950s, that autism was a response to 'cold' parenting. Bettelheim, it seems, continues to cast a substantial shadow.

Kerry also provides us with some insight into a common form of maternal response to felt accusations of inadequate mothering and to the societal expectation that women will do everything they can to 'fix' their child:

Basically I had to be the one to take steps. My husband didn't believe there was anything wrong. No one believed me. It sounded almost like I was a mad person. It got to the stage where I had to quit my job because I got tired of being called a 'high achiever'. You know some people might take that as a compliment. I took it as an insult in the end because there's only one too many times that you can hear that and then be told that you're actually transgressing your own goals onto your child. I wasn't doing that. In the end it was easier to say 'look, I'm a housewife' than say 'I'm a new business manager'.

Accused of being 'bad' mothers, and finding themselves in a situation of having to manage the added dependencies and requirements for intervention that are part of the expectations of having a child with autism, some women embark on a quest to prove themselves as 'good' mothers. While mothers of typically developing children can confidently expect that their offspring will move chronologically through the range from complete dependence to adult independence, mothers of children diagnosed with autism are told that their child may always require care. The entire imagined trajectory of their lives consequently alters. One response is to cling to conservative gendered moral rationalities that carve out motherhood as a sacrificial moral vocation.

Women thus struggle not only with the practical demands of caring for a child identified with autism; they also wrestle with ‘the mythography of the selfless Good Mother’ (Quiney 2007, p.32). In the end, as Kerry tells us, it is easier to say ‘look, I am a housewife’, ‘look, I am doing everything a good mother should do’. For these women, the identity of mother/carer ‘may attain greater salience than normal’ (Voysey 1972, p.88). Birenbaum observed the importance of achieving a ‘normal appearing round of life’ as part of a claim to conventionality for mothers of children with intellectual disabilities (Birenbaum 1970, p.196). Gil Eyal and colleagues (2010) have taken this observation further when they state that a ‘direct line of inheritance leads from this valorization of retarded existence to today’s autism world’ (Eyal et al. 2010, p.109). Autism parenting, they note, demands a moral mission of complete involvement; of endless, selfless care.

Mothers of children diagnosed with autism are thus expected, and expect themselves, to be mothers *par excellence*. These expectations are founded on gendered moral rationalities that animate notions of both good and bad mothering. The forms of stigmatisation mothers experience, at the point of school entry and in other domains of social life, are underpinned by these conservative ideologies of maternal blame and come to inform women’s own view of themselves. For mothers, dealing with stigma entails interpretive processes, which articulate their intersubjective experience of their child through, and sometimes against, expert definitions and advice (see Kelly 2005, p.200). Once we situate the experience of stigma within the domain of the intersubjective relationship of mother/child, we can more fully appreciate the depth of the threat to maternal identity that stigmatising encounters can pose. The demands of children identified with autism, and of the industries that provide therapies, services and education to these children, are such that mothers are forced to reconceptualise their futures. In the process, they often come to valorise the deep connectedness that is required by their caring role and to formulate it as a type of moral superiority. In the face of repeated stigmatisation and unrealisable demands for maternal perfection, they are left, time and again, crying in the park.

## **Conclusion**

Mothers’ school exclusion narratives point to the salience of experiences of stigmatisation in the lives of families of children diagnosed with autism. Although the diagnostic act exposes parents to disparate visions of appropriate action, ethical responses and future trajectories (Lilley 2011a,

p.154), all are likely, at particular points, to experience stigma. Mothers are especially vulnerable to what Goffman termed courtesy stigma.

I have suggested that the notion of courtesy stigma remains useful for encompassing a broad set of relationships. But in the specific case of mothers and their children, the term attachment stigma takes us closer to the heart of the stigmatising encounter because it more readily does the double work of referring to both the intersubjective mother/child relationship, often intensified and prolonged due to disability, and the role of mothering ideologies, informed in part by lay understandings of psychological discourses, in shaping stigmatising responses. In drawing on both sociological theories of stigma and on feminist work on the ethics of care, I have directed attention away from the strategising actor who haunts many scholarly accounts towards the affective complexities of stigmatising encounters, strategically mobilising a passing preoccupation with Winnicott to gesture towards the intersubjective dynamics underlying these moments.

School entry is, of course, an important moment in any child's trajectory; all sorts of consequences may flow from where and how a child is educated. My emphasis here, however, has been on school entry as a constitutive component in the moral careers of mothers of children diagnosed with autism. In saying this, I draw on Hollway's theorisation of maternal development; her insistence that mothers are not 'static and empty theoretical categories to be filled by their children's needs' (Hollway 2006, p.77).

The episode I have repeatedly invoked, of Cathy's tears in the park following a stigmatising encounter at her local school, is only a brief strip of time. In Hochschild's terms it is a short episode, or a 'still', from which long movies are composed (Hochschild 1979, p.557). Inside the frame, we found maternal anguish, a scene of commonplace suffering. If we zoom closer, we can make sense of some of the intense emotions involved through understanding the moral dilemmas and impossible expectations – the inevitable inadequacies – that cohere around the figure of the mother of a child identified with autism. If we run the film forwards, we see that the moral career of these women is shaped by certain types of encounters at particular moments along the timeline of their caring. Diagnosis, with its classificatory and objectifying procedures, forms one node on this line (see Lilley 2011b); school entry, with its exposure to the stigmatising practices of gatekeepers, is another. 'Certain events', Voysey dryly remarks, 'may be particularly instructive' (Voysey 1972, p.87).

Cathy's tale of crying in the park is a simple story that will be familiar to many mothers struggling with stigma, or, more simply, with the demands of small children. It could have been told by lots of people in different ways. As Margery Wolf (1992) reminds us, the feminist theorist listens to a range of voices and then chooses which story to represent in order to illustrate a situation of inequality or further a line of thought. We need to remember that mothers, too, strategically choose which stories to tell as they narrativise their experiences in the interview situation. The last time I spoke with Cathy, she prefaced some of her remarks by saying: 'Do you remember that story I told you about crying in the park?' I nodded but did not tell the extent to which that narrated episode has preoccupied my efforts to make sense of some of the dynamics of autism, mothering and stigma in contemporary Australia. Positioning the reader between two versions of this vignette, my authorial third person rendering and the immediacy of Cathy's first person narrative, has, I hope, helped the reader to hold the affective contours of the story in mind through the detours and byways of analytic reasoning, and to open out the possibilities that different readings and other good enough perspectives or theories might hold.

Goffman concluded that 'stigma and the effort to conceal it or remedy it become "fixed" as part of personal identity' (Goffman 1986[1963], p.65). Certainly the narratives of these mothers represent the grim weight of guilt, and shame, that accompanies contemporary motherhood. We have seen the ways in which these women are formed by, and struggle against, stigmatising views of their children and their mothering. Boxed within these brief stigmatising encounters, are women who struggle to be good mothers and who will continue to do so. Whether they are assessing therapies, looking for schools, thinking about post-school options or negotiating adult accommodation for their child, these mothers will keep on encountering stigma. The ambivalent complexity of their narratives demands that we understand their tears, and their recriminations, not judged against some standard of perfect mothering, but as efforts to formulate and enact projects of maternal care, and preservation of self, in the midst of pervasive fear of, and discrimination against, both mothers and their children diagnosed with autism.

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## **Chapter 6**

### **Publication #4**

#### **Professional Guidance: Maternal Negotiation of Primary School Placement for Children Diagnosed with Autism**

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# **Professional Guidance: Maternal Negotiation of Primary School Placement for Children Diagnosed with Autism**

This article explores the different forms of professional guidance negotiated by mothers as they search for a primary school placement for their child diagnosed with autism. The intensely contested terrain of whether segregated or 'regular' classrooms would be 'better' for the child shapes the contours of both professional guidance and maternal decision-making. Interviews with 22 women whose children were about to start primary school in Sydney, Australia, allows an exploration of the ways women engage with or reject professional guidance, offered by paediatricians, psychologists, early intervention professionals, and education providers. Mothers frequently received conflicting professional guidance, and felt conflicted about their schooling decisions, especially when students are labelled 'borderline'. Overall, recent suggestions of a democratisation of autism expertise are not supported by this research, which underlines the need to analyse both the agency of mothers and the power differentials that continue to exist between families and experts.

**Keywords:** autism; mothers; experts; professional guidance; inclusion; exclusion

## **Introduction: The Autism Matrix?**

There are many different ways of knowing about autism, underpinned by various therapeutic approaches and shaped by a range of disciplinary orientations, including paediatric medicine, psychology, early childhood, education and the various specialties practised by those involved in interventions, such as speech pathology and occupational therapy. In this article I investigate how professional guidance is applied to and interpreted by mothers whose children diagnosed with autism [CDWA] are about to start primary school in Sydney, Australia. This transition makes considerable demands on children, families, educators, and other professionals as key players may present very different views regarding the best 'placement' for CDWA (Foster, 2005, p. 71). In the following I focus broadly on primary school 'choice', and more specifically on the intersections between autism knowledge, expert advice, and maternal agency.

Frequently labile interweaving between 'experts' and 'parents' have done much to shape the shifts in understanding about autism, most notably from a psychological to a neurological disorder (Silverman, 2012). Gil Eyal and colleagues' (2010) sociological tour de force on the history of autism invokes the compelling image of an 'autism matrix' as one way of understanding the ways in which relations of expertise have been successively reworked to

create a global ‘assemblage’ within which the autism spectrum has become the paradigmatic childhood disorder. This matrix, the argument runs, is characterised by a democratisation of expertise. With deinstitutionalisation and community treatment, psychiatry lost its monopoly over the treatment of autism. Now special educators, occupational therapists, behavioural psychologists, and the myriad professions that provide services and advice about autism are all on an equal footing within the matrix as they seek to strike alliances with parents. This network of expertise is occupied in various increasingly intense ways with the surveillance of childhood and the provision of a therapeutic regime.

According to this model, parents have been the prime force propelling this democratisation of expertise and the expansion of the autism matrix. The notion that autism expertise has been democratised and that parents are pivotal producers, as well as consumers, of autism knowledge certainly holds true for some mothers and fathers, especially those in the public arena as experts and/or activists. While Eyal and colleagues have undertaken most of their research in the USA, they perceive the autism matrix as a global phenomenon. I am concerned to see how apt this model seems if we shift our attention geographically, from the USA to Australia; shift the period of time focused on, from the therapeutic imperatives of very early childhood to the start of elementary schooling, where the education system becomes the key provider of services to CDWA; and if we listen to the experiences of diverse parents. In these altered circumstances, does the notion of a current democratisation of autism expertise, eliding many of the power differentials between families and professionals, stand up to scrutiny?

The research presented here is part of a broader study titled *Maternal transitions: When children with autism start primary school*. The design of this doctoral research is longitudinal, with up to 3 interviews being conducted with each participant over a three- year period. Purposive sampling was used to allow access to mothers whose children were experiencing various levels of school inclusion in special schools, support classes, and regular classes. Participants were largely recruited through early intervention providers and relevant parent support groups. The material used in this article derives from three sets of interviews, conducted between 2009 and 2011 with mothers of CDWA who were, in 2009, transitioning to primary school the following year; 22 mothers participated in the first round of interviews, 21 of these women were interviewed again in 2010, and 19 participated in the final interview round in 2011.

Across a number of indicators they are a diverse group. The mothers ranged in age from 29 to 48, and in educational level from high school dropouts to postgraduate degree holders. Twelve reported annual household incomes above A\$100,000, while 3 had incomes below A\$50,000. When visiting these women, their home environments ranged from tiny crowded apartments in lacklustre suburbs to architect-designed mansions in blue ribbon locations. The majority of participants identified as Anglo-Australian; however, the sample included three mothers of Italian background, one Vietnamese, one Lebanese and one white South African. At the conclusion of the entire set of interviews three of the women were single mothers.

Semi-structured interviews were undertaken, usually in the participant's home. Topics discussed included experiences of diagnosis, early intervention, and processes of school placement. Interviews lasted from 60 to 90 minutes. Each was recorded and transcribed in full. My aim throughout was to encourage mothers to give their own accounts of experiences with professionals across a range of sectors, including medicine, psychology, early intervention, and education. The conversational nature of the interview frequently yielded lengthy accounts of significant events and maternal negotiations of the complex professional world they, of necessity, encounter once their child is diagnosed. All of these women were aware that I, also, have a child on the spectrum.

In the first interview I asked mothers what sources of professional advice they received and whose opinions were formative in the decision about where their child went to primary school. Mothers thus spoke about expert advice that seemed salient to them at the time of interview. Occasionally mothers referred spontaneously to the factors impacting on their child's first school placement during the second interview. This was especially the case when children had changed settings.

This article is informed by the full set of 62 interviews conducted with all transcripts checked. Any interview material on the processes of deciding on *initial* school placement, with particular reference to the advice mothers received from professionals, was extracted for analysis. This included the full set of first interviews (22) and six of the second interviews. Working within the broad qualitative methodological framework of narrative analysis, I thematically interpreted this interview data (see Riessman, 2008). Pseudonyms are used throughout and minor details have been altered to protect the anonymity of participants, their children, and many of the service providers they refer to.

## **Professional Guidance**

Choosing a school for any child ‘often emerges as a complex and confusing business’ (Ball & Vincent, 1998, p. 386). For parents of CDWA, the interplay of arguments regarding the importance of educational ‘inclusion’ versus the advantages of special education expertise, of intense concerns about their children’s future, and of multiple sources of professional advice, make the process time-consuming and often emotionally exhausting. A number of the women I interviewed summed up the overall experience of choosing a primary school for their CDWA as a ‘nightmare’ (see Lilley, 2012a).

Mothers undertake most of the labour involved in school ‘choice’ (Wilkinson, 1996); research repeatedly underlines this engendered dimension of school choice in Australia (see Aitchison, 2006; Campbell, Proctor, & Sherington, 2009), especially when children have additional needs (Wilkinson, 1996). When I asked mothers what kinds of information they used as a basis for giving consideration to choice of school, they referred to a wide variety of sources, including the Internet, pamphlets, and parenting magazines. Most, however, indicated that it was advice received in face-to-face encounters that was pivotal in the process of opinion formation and information sorting. In this article my focus is purely on professional guidance about initial primary school enrolment.

Currently in New South Wales [NSW], students with a disability, including autism, can be enrolled in a regular class, in a Support Class in a regular school, or in a Special School. These options are available in the government, Catholic and Independent education sectors. Parents may also elect to educate their child at home either through accessing distance education or home schooling. All children have the legal right to attend their local government school.

In recent decades there has been a significant increase in autism diagnosis; it is an increasingly common component of the ‘developmental landscape’ inhabited by clinicians, educators, children, and parents. Due to high rates of behavioural disturbance and, often, very uneven cognitive abilities, CDWA are perceived as making considerable demands on existing educational services (Howlin, 1998). Parents are caught between conflicting advice that segregated school placements (with smaller classes and special education expertise) or regular classes (with ‘normal’ peers and higher academic expectations) will be best for their child.

Parents often find the period spent researching and deciding on where to send a CDWA to primary school intensely confronting. Many have been involved in intensive early intervention aimed at ‘normalising’ their child. As the child reaches primary school age, it



becomes apparent that they may still require special services and that they differ, often noticeably, from most of their peers. Parents are informed that ‘the provision of appropriately structured educational programmes is one of the most important aspects of successful treatment’ (Howlin, 1998, p. 316). The stakes are frighteningly high. To think of school choice as a straightforward rational event is to miss the crucial affective components of this process (Ball & Vincent, 1998).

Deinstitutionalisation (the closure of total institutions), and the accompanying ideology of ‘normalisation’, was a pivotal trend in the care of people diagnosed with autism, as well as other developmental disabilities and psychiatric conditions, during the 1970s (Silverman, 2012, p. 133). Normalisation was an essential component of the new social contract to be forged between the state and previously excluded individuals who were now to become citizens entitled to civic rights and social services that would help to ensure their participation in ‘the least restrictive environment’.

Providing the goal of normalisation involves an ongoing assessment of both individual potential and risk (to others and to self). The cooperation of multiple experts is required to set children on differential tracks, sequentially ordered to adjust to their abilities and give, at any point in time, the maximum amount of integration, or inclusion, possible. Or so the theory runs. These ‘forks in the road’ (Siegel, 1996, p. 274), most crucially (but not only) occurring at the transition to primary school and then secondary school, require ‘a sort of medico-pedagogic expertise capable of justifying the assignment of “atypical children” into distinct tracks’ (Eyal et al., 2010, p. 121). Once the exclusive preserve of psychiatry, various professions now struggle to claim they have the greatest legitimacy to engage in this diagnosis of social destiny (Fulcher, 1986).

One often hears this phrase ‘least restrictive environment’ in current discussions of educational placements for students diagnosed with autism (Eyal et al., 2010, p. 65, 108). In NSW, a growing number of legal instruments support policy shifts towards educational inclusion ensuring, in theory, that students with disabilities and ‘special needs’ are able to access and participate in education on the same basis as other students (General Purpose Standing Committee [GPSC], 2010). Part of what makes this process so complex is that the rubric of autism is now ‘so imprecise that it tells us mainly that the person has deficits in communication and social interaction, has restricted interests and activities, and falls somewhere between profoundly mentally retarded and exceptionally intelligent’ (Grinker, 2008, p. 163).

This research reflects that variability. The 22 mothers interviewed all had children who were about to start school and were between 4 and 6 years of age. They represented the full range of diagnoses then constituting the autism spectrum, including Autistic Disorder (9 children), Asperger's Disorder (1 child) and Pervasive Developmental Disorder - Not Otherwise Specified or PDD-NOS (4 children).<sup>6</sup> Eight were described as having 'high functioning autism' [HFA]. Seven had an additional diagnosis of moderate to severe intellectual disability [ID]. Eleven of the children were initially enrolled in regular classes and 9 in segregated classrooms (2 in Support Classes and 7 in Schools for Special Purposes or SSPs). One woman was home schooling and another had not yet enrolled her child anywhere. None of the children attending regular classes were classified as having an ID. When the interviews concluded, 11 of these children were in segregated settings, and 11 were attending regular classes. There was considerable flux between these settings, usually in the direction of more segregated provision.

### **Conflicting Advice and Conflicted Mothers**

All of the mothers interviewed referred to multiple sources of professional involvement with their CDWA. At a minimum, these families engaged with speech therapists, occupational therapists and early childhood educators, some of whom had special education expertise. Many were immersed in time (and money) intensive forms of early intervention such as Applied Behaviour Analysis [ABA] or Relationships Development Intervention [RDI] (see Lilley, 2011a). Where this was the case, the advice of these therapists was influential in the process of maternal opinion formation. Most mothers sent their child for a psychometric evaluation in the year prior to primary school enrolment.<sup>7</sup> These evaluations were also often crucial in informing the views of both professionals and mothers about where a child should go to school.

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<sup>6</sup> At the time this research was conducted diagnoses of autism in Australia were made according to criteria specified by the American Psychiatric Association's Diagnostic and Statistical Manual- IV, Text Revision (DSM-IV-TR). The DSM-IV-TR identified a set of Pervasive Developmental Disorders that are considered autism spectrum disorders, including Autistic Disorder, Asperger's Disorder and PDD-NOS. Under the revised edition of the manual (DSM-V), published in May 2013, there will simply be one umbrella diagnosis of Autism Spectrum Disorder, with distinctions made according to levels of severity ([http://www.autism.com/index.php/news\\_dsmV](http://www.autism.com/index.php/news_dsmV), accessed 7 February 2013).

<sup>7</sup> Mothers are often advised to book a psychometric test for their CDWA in the year prior to school entry. This is partly so that a student who is potentially eligible for extra government funding in NSW can have their disability assessed and confirmed using DEC Disability Criteria. Eligible funding categories include autism and ID (GPSC, 2010, pp. 12–13).

Earlier in the year prior to school entry, mothers mainly listened to the guidance offered by early intervention professionals [EIP]; as the year progressed, the views and decisions of school bureaucrats and educators became increasingly important. The maternal work of assessing these various sources of information and advice was sometimes experienced as overwhelming. Many mothers were conflicted about whether it was best to send their child to a segregated setting (either a Support Class or a SSP), or a regular classroom. Some were unsure about whether the Catholic, Independent or government education sectors would better serve their child. Still others wrestled over the different forms of schooling available within one sector. For all, the decision about where their son or daughter should go to school was perceived to be pivotal in both remediating deficits and enhancing academic and/or social capacities and abilities.

Because of the involvement of multiple experts over the course of early intervention and school enrolment, mothers frequently received conflicting professional guidance, and felt conflicted about their schooling decisions. This conflict is both partially constituted by and formed in reaction to inclusive education policies and debates, which are premised largely on social justice considerations. Of the 22 mothers interviewed, 5 reported that there was no conflict in the professional guidance they received. Three of these 5 women were not conflicted about their decisions.

Professional guidance is not conflicting when different experts engaged in the school enrolment process all agree about the best type of educational setting for that particular child. There may be different opinions expressed about which SSP would be better or which mainstream primary might offer more services. Nevertheless, there is basic agreement about what sort of classroom a child should attend. However, even when this is the case, mothers may feel conflicted. This is because they are in a double bind. In particular, the presence of both segregated and mainstream education options means that mothers are never sure that they are doing the 'right thing'. Those directed towards the mainstream may wonder if their child would be better off in a support class with autism- specific educator expertise. On the other hand, those directed towards segregated provision may wonder about the long-term effects of exclusive classroom exposure to other children with developmental difference. They may also be aware of the social justice arguments that animate the push towards inclusive education. The presence of different sectors of the education market may add to this sense that if they only tried harder they could find something better.

In the following I draw a distinction between limited and strong conflict experienced or felt by mothers as these somewhat rough divisions help us to understand their situation. I previously mentioned that 3 of the 22 mothers interviewed, experienced no substantive conflict. Six experienced limited conflict that did not impact greatly on their decisions. The majority (13) reported strong conflicts in relation to their child's school enrolment. In seeking to understand these dynamics, the following sections outline the experiences of mothers according to how their children have been labelled and classified during transition to primary school. The most crucial classificatory division applied to CDWA is between those who have a confirmed ID (either 'moderate' or 'severe') and those who are seen as having normal intelligence. Children who are described as 'borderline' occupy an especially ambiguous position in relation to school placement. Professional guidance was most conflicting for this latter grouping.

It is important to note that there have been many robust critiques of the historical uses of psychometric testing as an expert tool of the state (Kapferer, 1990, p. 42) used to legitimate the segregation and eugenic control of ethnic minorities and people with disabilities, with particular emphasis on the reductionist and contradictory notions of intelligence presupposed by IQ tests (see Richardson, 2000, especially Chapter 2; Snyder & Mitchell, 2006), as well as the difficulties of testing individuals with autism (Edelson, 2006). Nevertheless, such testing remains a crucial weapon in the arsenal of 'appropriate' school placement, and may be used to legitimate enrolment in both regular classes (when a child is assessed as having an IQ within normal range) and segregated classes (when a child is found to have an ID as well as autism). To understand conflicts in professional guidance, and their impact on families, we need, therefore, to investigate the types of expert advice offered about children who fall into these categories because whether or not we accept them as useful descriptors they are social facts – professionals classify and think about children according to these categories and families, too, may either come to accept or reject these psychometric evaluations as indicative of the potential and personhood of their child (see Lilley, 2011b). In this way, such categorisations have performative effects.

### ***Students diagnosed with autism and intellectual disability***

Seven of the mothers had children diagnosed with both autism and a moderate to severe ID. Six were clearly directed by professionals towards special schools. One child, with a recent diagnosis

of Autistic Disorder and moderate ID, was the source of both professional and maternal dissension in relation to school placement.

Two of these mothers had no hesitation in sending their child to a special school. Bridget was advised by EIP that Miranda, who was non-verbal, would benefit most from a special education placement in primary school. Although the school counsellor at her older daughter's local government school told her that she had a right to enrol Miranda there, Bridget never seriously entertained that option. 'I didn't feel she'd get that special education from a teacher who specialises in it; I didn't feel she'd get anywhere', she explained. Felicity has two children diagnosed with developmental disabilities and ID. Her older son already attended an Independent Catholic special school, which she had originally been advised to consider by EIP. She actively sought an enrolment for her daughter at the same special school.

Following advice from EIP and government school disability consultants [GSDC],<sup>8</sup> Alyce enrolled her daughter Annalisa in a nearby SSP (see Lilley, 2012b). Initially she struggled with this decision:

Was I thinking right about it, and what really did Annalisa need? Was it just my wish that she wanted to go to mainstream and be normal, as such? And I realised, no, she won't cope, she won't cope, and I want her to be happy. And that's more important to me, than whether she's normal.

Dung visited a number of special schools. After listening to the opinions of EIP and GSDC she complained that there had been 'too many opinions' about the best placement for her son, Giang. With very limited English and few financial resources, Dung was highly reliant on the EIP who had been working with Giang in the preceding years. While she remained satisfied with her decision to enrol him in a government SSP, over the years she repeatedly told me that her friends and her husband remained sceptical about this choice, arguing that her son might learn to speak if placed in a Support Class with children who were more verbally able. For both Alyce and Dung the decision to send their child to a SSP was fairly straightforward. All the professionals they spoke to advised this would be the best option. For both mothers, however, the simultaneous provision of segregated and regular classroom options for CDWA in NSW resulted in cross-cutting pressures that remained a source of felt tension and ambivalence.

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<sup>8</sup> This position has now been phased out. Their job, according to official documents (e.g. NSW Department of School Education Special Education Directorate, 1997), was to give families 'information about the full range of school options and appropriate personnel to contact'.

Hannah was in direct conflict with the consultant assigned to her by the government education system. Referring to a telephone conversation with this GSDC, this mother said: 'She rang to tell me that she didn't think a Support Class was the appropriate setting. That they thought, they being the Department of Education, thought that he needed to be in a special school.' Hannah, who was a highly educated professional, rejected this pressure, insisting on a Support Class placement for her son.

Especially in the Independent sector, special schools vary widely in their educational philosophies. Thus, while a mother may come to agree that her child should attend a segregated school, there may be substantial disagreements as to which one would be best. Carmella was strongly advised by a special educator that her son, Guy, should attend an Independent SSP with a reputation for focusing on academics and using behaviourist methods. This was also the school favoured by her husband. Instead she chose another Independent SSP, with an emphasis on sensory processing and music. Carmella insisted on her maternal authority in making the final decision, frequently utilising the tropes of 'maternal intuition' and 'gut feeling' to explain her actions.

Kerry's son, Toby, had a relatively late diagnosis of Autistic Disorder at age 5. Still struggling with the emotional impact of diagnosis, she felt that she was given conflicting and vacillating advice by EIP. Deterred by the mainstream Catholic school her older daughter attended, through the Principal's appeal to insufficient resources, Kerry's narrative invoked a lack of maternal agency. Hers was a story not of school 'choice' but of school 'placement'. At one point she was advised by EIP that her son 'belonged' in a Support Class; at another that he 'belonged' in mainstream. Kerry paraphrased the professional guidance offered: 'He will either be the top of the supported class or at the bottom of a mainstream class; the choice is yours'. This mother firmly rejected making what she saw as an impossible decision: 'They chose the schools, I didn't. I didn't even want to choose the school to be honest with you'. Eventually Toby was enrolled by the GSDC in a Support Class. Kerry refused any further interviews.

Amongst this group of 7 mothers of students diagnosed with autism and ID, there was a wide range of experiences of professional guidance about primary school 'placement'. All received multiple sources of advice. Two (Bridget and Felicity) were confident and upbeat about their children's enrolment in special schools; two received consistent advice but were conflicted about segregated versus mainstream provision (Alyce and Dung); two (Hannah and Carmella) experienced conflict about the type of segregated education that would be preferable, and one

(Kerry) reported vacillating and conflicting advice. Even when operating within a limited framework of possibilities, mothers tended to stress their own agency. However the contrast between the active term school ‘choice’, which is said to apply to all parents of children starting school, and the passive term school ‘placement’, which is something that happens to children who have diagnoses of various kinds, sums up the anguished contours of Kerry’s story.

### ***Students diagnosed with autism and labelled ‘borderline’***

Six mothers had CDWA they described as ‘borderline’. This is an ambiguous category rather than a diagnosis. Generally it is a categorisation of intelligence wherein a person is tested as having below average cognitive ability (usually an IQ of 70–85), but not ID (70 or below). This is complicated by the characteristically uneven cognitive profile of people diagnosed with autism. Further, sometimes the term is used to indicate a person who exhibits fewer core autistic traits and is therefore seen as being on the edges of the autism spectrum. Those with a diagnosis of atypical autism or PDD-NOS may fit this description. In other words, the term ‘borderline’ may be used by autism professionals and families alike to loosely describe those who are judged to either potentially be more intelligent or be less autistic than some other individuals diagnosed with Autism Spectrum Disorders [ASDs].

All of the mothers of borderline children received conflicting professional guidance and found the process of transition to primary school difficult. The reasons for that difficulty were varied. All were caught in the divide between mainstream and segregated education possibilities, feeling uncertain about where their child should go to school and juggling varied professional opinions about that issue. Some referred to a lack of places available in segregated schools or classrooms; others were concerned about a lack of resources to help their child in the mainstream. One mother struggled to understand her options, giving the impression of labyrinthine bureaucratic systems that she was unable to comprehend.

Gemma enrolled her son, Harry, in an autism-specific special school when he was four-years-old. A special educator strongly advised against this: ‘Lauren had said to me “There’s no way this kid’s going to a special school; we’re getting him ready for mainstream”’. At this point Gemma viewed her son’s segregated placement as transitional and as providing therapy 5 days a week, which otherwise she could not afford. Sarah was advised by a developmental paediatrician (who was part of a multidisciplinary assessment team) that her son would benefit from autism-specific schooling. However, the EIP providing therapy to David all pushed her towards the

mainstream. She rejected the paediatrician's concerns, largely on the basis that they had an overly negative and stereotypical view of David. As far as she was concerned, EIP knew her son much better, and the hope for his development that they enacted in their work was far more palatable than the attempted pragmatism of a diagnostician. After the paediatrician told her that David would 'never be fully independent' and 'never have a relationship', Gemma refused her perspective entirely: 'So that's when I thought, "Oh, I'm not going to listen to them." I just feel sorry for families, like myself, who hang on to their every word because you think "Oh, they're professionals"'.

Sasha followed the advice of her son's RDI therapist after investigating segregated and mainstream schools in the Catholic, Independent, and government sectors. Told by a GSDC that her son was unlikely to qualify for much funding or extra resources, and refused enrolment at a Catholic school she felt might be suitable, Sasha then visited an Aspect special school.<sup>9</sup> She was, however, distressed by the dilapidated buildings and general sense, as she perceived it, of severity. She home-schooled Tony.

Natalie provides a stark example of the disappointment and confusion mothers may feel when professional advice changes over time. She succinctly outlined the educational dilemma faced by parents of 'borderline' students: 'He's too high functioning to go into a special needs kind of a school, and to put him in an autism Support Class I was a bit worried about him developing more behaviours'. She went on to describe her anger when the EIP involved with her son's ABA therapy suggested that Evan was 'not ready' for a regular classroom in the mainstream:

So all these people that had told me, 'Of course he will be mainstream; that's the right thing for him to do', have suddenly turned around and gone, 'Shit, there's big problems.' And I was getting to the point where, like, I want to swear, it was just like, well, fuck, he's autistic, I can't cure autism. Like, it's not going away. Hello? This is it. What do I do? Where do I put him?

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<sup>9</sup> Aspect (Autism Spectrum Australia, 2012) provides autism-specific education in either satellite (support) classes or 'base' schools throughout NSW. They are part of the Independent education sector but have agreements with both the government and Catholic systems. In 2012 they catered to approximately 800 students.



Natalie weighed up her options and, against the advice of EIP, enrolled her son, who had a tendency to run off impulsively, in their local DEC school after a successful application for high perimeter fencing was made.

Libby applied for a number of government support class placements for Zeke, but never heard back. She went ahead and enrolled him in the mainstream school his older sister attended. An indefatigable optimist, she decided it was ‘for the best’ and never pursued the bureaucratic trail of her submitted paperwork. Hilary, too, had difficulties making headway with bureaucracy. She attributed her inability to navigate the government education sector to poor dissemination of information, and she explicitly linked this difficulty with accessing and understanding ‘the system’ to a sense of maternal powerlessness:

With the standard information and that’s not being familiar with how things work I just felt a bit lost and powerless. There’s a lack of information as to what will be offered. So, I don’t know how it all works and how they make their decisions. But it is very hard to work it out from the outside looking in and there’s no guarantees that you could go somewhere else anyway.

Hilary enrolled her daughter in their local government school. This decision was largely made because it was the option she knew about and could afford. This perplexed powerlessness was a strong theme of her conversation:

Well, I didn’t know what to do. I had no idea. I was just going by whatever professional whispered in my ear latest, I think, because I had no idea. I’d never dealt with it before. I didn’t really know any other mums in the situation.

Her difficulties were compounded by her daughter’s capacities. As she put it, ‘It’s just really hard because people just assume that there’s nothing wrong with her and it is only when they get to know her that they really start to notice that she’s more difficult to manage than other children’.

### ***‘High functioning autism’ students***

Nine mothers had children they described as HFA (8 children) or Asperger’s (1 child). HFA is not a diagnostic category; it is a widely, and loosely, used informal term. Commonly, it refers to individuals who clearly do not have concurrent ID but also do not fit the criteria for Asperger’s

Disorder (often due to delayed language acquisition). In everyday usage there is a lot of slippage between the term HFA and Asperger's, with the latter being less stigmatising. One of these 9 mothers was satisfied with the choices available, 4 reported limited conflicts, and 4 described substantial conflict during the transition process.

Helen's son, Glen, was nearly 6 years old when he was diagnosed with autism. He is enrolled in his local government school, which is directly across the road from their modest apartment. Helen, a single mother, briefly considered sending Glen to another government primary because he attended its feeder preschool. However the proximity of the local school combined with its 'good name' were decisive factors. Further, Glen's developmental paediatrician as well as a number of other professionals, including an autism outreach teacher who worked across multiple primary school sites,<sup>10</sup> supported her decision.

Sally chose an Independent Christian school for her son, Todd. Her older son already attended the school. When she disclosed Todd's diagnosis she described a stigmatising response, saying the school acted like he had 'a stain'. However, once they had observed him at preschool their attitude improved. All of the experts she spoke with, including the hospital diagnostic assessment team, an educational psychologist, preschool teachers and an EI therapist assisting with school transition, advised a regular class in a mainstream school. Sally's Christian faith, existing membership of the school community and their comparatively smaller class sizes all informed her decision.

Callum's family devoted substantial resources to his ABA therapy. The ABA therapy team was 'adamant' that a regular class in a mainstream school would be the best option. Other professionals, including a prominent developmental paediatrician, agreed. 'We go with what the experts tell you', Melissa explained. Reflecting later on her son's subsequent move to an autism-specific class and then school, both run by Aspect, this mother divulged that the negative evaluation or 'very bad impression' of Aspect schools given by the ABA centre had also had a strong impact on her initial decision to send Callum to his local school.

Both Melissa and Sally were somewhat uncertain about their choices as part of their recognition of, and responses to, the tensions (negative descriptions of particular schools by early intervention providers) and shortcomings (a reluctance to enrol CDWA) in parts of the education autism landscape in NSW. Phoebe enrolled her son in their local Catholic school. Although

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<sup>10</sup> This position has also been phased out in NSW. Under the current School Learning Support Program model, a number of specialist positions have been merged into a single support teacher role.

content with this, she spoke at length about the difficulty of placing students with HFA. She believed that ‘lower functioning’ children were better catered to.<sup>11</sup> Joanna initially thought an Aspect satellite class might be ideal for her son but said that not being allowed to observe one of these classes was ‘off putting’. Her attempts to elicit information about disability options from DEC were so unsuccessful that she described this government department as ‘a closed door’. Having also been advised against the Catholic system, on the grounds of large class sizes and insufficient resources, by a developmental paediatrician, she enrolled her son in their local government school. While she was satisfied with her ‘choice’ she was also aware of a field of possibilities that progressively narrowed as she searched for the best classroom setting.

Gaby’s son, Lance, was diagnosed with Asperger’s aged 5 years. Her older son attended an Independent progressive school. She hoped Lance would go there. However, the school manager refused to enrol him. The emotional impact of this refusal was compounded by the double bind advice this woman gave her: Gaby was told that this mainstream school was unable to provide Lance with sufficient help but that he might copy ‘behaviours’ if he went to a segregated classroom. Eventually, after considering prolonging his preschool enrolment, Gaby placed Lance in a Support Class for children with mixed developmental disabilities at an Independent Catholic school.

Angela was advised by all the EI therapists involved with her son, Jarrod, that he should attend a regular class in a mainstream school. However, she chose an early enrolment, aged four, for Jarrod at an Aspect base school, reasoning that this autism- specific setting would be the ideal environment to assist with his eventual integration in a mainstream class. A strong sense of maternal agency, rooted in the fact that both she and her husband had worked in the disability sector and thus were themselves experts, animated her decision. Cathy, on the other hand, decided to send her son, Nicholas, diagnosed with PDD-NOS, to a mainstream government school. This was explicitly against the advice of an ABA therapist. This mother had previously trained and worked as a teacher. As a result of further study, she became ‘committed to the notion of inclusive education’. Again a sense of her own capacity as an expert enabled her to make a decision that conflicted with some of the professional guidance she received.

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<sup>11</sup> A report published by Autism Spectrum Australia in May 2012 highlights the significant unmet needs of individuals who have an ASD and no ID, including poor educational experiences characterised by insufficient learning support, social isolation and bullying.

A developmental paediatrician advised Hope that her son Mark was ‘fine to go to a mainstream school’. His preschool teacher agreed, saying that ‘he would fit fantastic’ in a regular class. When this mother filled in the enrolment form at her local DEC school, the Acting Principal told her ‘no, we don’t take special needs children’, adding that they could damage the school’s academic reputation. It was only after Hope escalated this further up the DEC bureaucracy that Mark was enrolled (see Lilley, 2012a).

The conflicts described here stemmed from numerous sources – sometimes EI therapists disagreed with school gatekeepers; sometimes mothers disagreed with EI therapists; sometimes autism professionals disagreed with one another. These conflicts all attest to the perceived difficulties of placing students who have both academic potential and enough unusual behaviours and difficulties to lead to an autism diagnosis.

## **Conclusion**

As the number of children diagnosed with ASDs has radically increased, so has the pressure on the education ‘system’ in NSW (see Graham & Sweller, 2011). When faced with increasing demand for either segregated placements or mainstream placements with support, education professionals adopt a variety of pragmatic strategies in an effort to minimise the impact of these demands. These strategies can include deflection (suggesting to parents that their child would be better served elsewhere, either in another school or another sector of the education provision system) and denial (refusing to enrol a child). I have documented some of these processes in an article analysing maternal narratives of informal school exclusion at the point of transition into primary school (Lilley, 2012a). Some women overtly resist these exclusionary strategies; others manoeuvre around them or internalise the moral logic of exclusion (Lilley, 2012b), which may posit their CDWA as a risk to be managed by those with special expertise. They also negotiate the different forms of autism knowledge, with varied orientations towards what might constitute the best classroom environment for students with autism, to be found across complex webs of service provision spanning medicine, health, early intervention and education.

In this article I have focused on the varied advice offered by professionals to mothers whose CDWA are about to start primary school. Different ways of knowing about autism, informed by diverse disciplinary frameworks may produce differences of opinion. However, the extent to which mothers are subject to conflicting professional guidance is most clearly related

to where their child is placed on the autism spectrum. Mothers whose CDWA had a concurrent diagnosis of ID were all directed towards segregated provision. The majority of mothers whose children were described as HFA were guided towards mainstream education provision, though in these cases conflict may arise between professionals involved in the early and preschool years (who usually recommend a regular class) and school gatekeepers who attempt to exclude or deflect these same students. The most intense conflict was experienced by mothers of children labelled 'borderline'. For these students, the 'forks in the road' that are clearly signposted for those with autism and ID (who are led towards the cul-de-sac of segregation) and those considered HFA (who are usually directed towards the mainstream) are less legible. Professionals are very uncertain of both the potential of these 'borderline' children and of the best classroom 'setting' to ameliorate their difficulties.

Mothers respond in varied, and creative, ways to these conflicts and to the tensions inherent in the co-existence of both segregated and mainstream classes, as well as the possibilities for 'choice' implied by the presence of competing sectors of the education market. Given this, mothers may feel conflicted about what is best for their CDWA even when all professionals are in broad agreement. Women want to help their children; they want to be and be seen as 'good' and competent mothers. The uncertain and intensely moral context of mothering a CDWA leads some mothers to seek out and prioritise what they perceive as expert knowledge. Others feel overwhelmed becoming disengaged with the process (see Miller, 2005, p. 48, pp. 86–87). As one mother confided: 'I think it's a real sense of loss, of just feeling incompetent, ineffective ... My perception of myself and my self-confidence, I think, just plummeted.'

Mothers negotiate, resist, manipulate and reproduce the professional guidance offered to them during this transition period. In analysing this transition we need to remain sensitive to both the agency of mothers in relation to professional guidance and the power differentials that continue to exist between families and experts. This power differential, and its frequently negative impact on school inclusion for students with disabilities, has also been documented elsewhere (Wilkinson, 1996). We are in the terrain of what Slee and Cook (1999, p. 267, 276) critique as 'forms of expert knowledge which are in and of themselves disabling' with professional knowledge sometimes contributing to 'the discriminatory educational fabric of Australian schooling'. But it is also important to note that professionals, especially those involved in EI,

may well recommend more inclusive forms of education, especially when students are labelled either borderline or HFA.

Let's circle back now to Eyal and colleagues' model of the autism matrix, outlined at the very beginning of this article. Certainly the suggestion that the autism matrix is populated by numerous professions that provide services and advice to families is borne out by this research. If we confine our interest for a moment to these professionals, and the relationships between them, we can see that no one occupies, if you like, a commanding position. Paediatricians, psychologists, therapists, and educators all vie to have their opinions heard and their advice taken regarding the best school placement. This might legitimately be described as a democratisation of expertise.

We need to remain aware, however, that at different points in the biographical trajectory of a CDWA, different experts exert more or less leverage, both with bureaucracies (such as schools) and with parents. For instance, the assessment of an educational psychologist who undertakes a psychometric test may prove crucial in determining how a child is thought about and where they are placed. At critical points, then, there is a hierarchy of professional influence over school placement.

If we widen our gaze to look at the relationship between professionals and parents, an even more hierarchical picture emerges. The narratives of these mothers do not suggest a democratisation of expertise. Certainly mothers exercise agency, questioning professional guidance, seeking expert advice and attempting to manipulate the outcomes of primary school placement. Usually, however, they do not present themselves as equal partners with professionals. Rather, they do their best to manoeuvre within, and sometimes around, the limited, and often limiting, possibilities offered by the current education autism landscape. In undertaking that complex task these women usually conveyed a sense of embattled vulnerability that points to the continuing force of hierarchical power differentials between those who offer professional guidance and those who must listen to it.

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## **Chapter 7**

### **Publication #5**

#### **Rumour has it: The Impact of Maternal Talk on Primary School Choice for Children Diagnosed with Autism**

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# **Rumour has it: The Impact of Maternal Talk on Primary School Choice for Children Diagnosed with Autism**

This article explores the pivotal role of rumour in shaping primary school choice decisions for parents of children diagnosed with autism. Drawing on semi-structured interviews with 22 mothers conducted in Sydney, Australia, this study points to the varied functions of grapevine knowledge about schools gleaned in diverse contexts, including early intervention settings, support groups and neighbourhood communities. Parents, especially mothers, provide one another with pragmatic information about schools as well as advice on how the education 'system' works. They also repeat 'horror' stories of bullying incidents and social exclusion that have a powerful affective force. Educational sociologists have referred to this as 'hot' knowledge. These data demonstrate the need for more detailed analyses of hot knowledge in understanding how families of children diagnosed with autism make choices between segregated and mainstream education options, as well as deciding on particular schools or classrooms within the various sectors of the education market. In studying these processes, we gain a better understanding of how mothers negotiate multiple forms of knowledge during periods of school transition and of the importance of this process in forging maternal identity. The qualitative research presented helps us to conceptualise broader processes of social inclusion and exclusion experienced by these families.

**Keywords:** disability; inclusive education; autism; school choice; mothers; rumour

## **Introduction**

In this article I explore the role of information exchange between mothers in shaping decisions about which schools and classrooms their children diagnosed with autism will attend in their primary years. The study is located in Sydney, New South Wales (NSW). The linked issues of how mothers negotiate their child's primary school placement, and of the ways in which that negotiation shapes maternal identity, are central to this research. Previous investigation of the impact of professional guidance on school choice for these families has pointed to the centrality of maternal labour in securing primary school enrolment as women engage with complex webs of service provision (Carpenter and Austin 2008; Lilley 2014; Wilkinson 1996). However, this emphasis on professional guidance only tells part of the school placement story.

Rumour is often conceptualised as a pathological phenomenon spreading inaccurate ideas (Shibutani 1966). This pathologisation of rumour inhibits understanding of its complex uses. The argument made here is that maternal talk should be listened to and acknowledged as an

integral part of the process whereby decisions are made about children diagnosed with autism, including the decision to enrol students in either inclusive or segregated settings.

In the following, I draw on both maternal gossip and maternal rumour. Gossip is generally defined as restricted to small local groups in which members know one another intimately. Rumours, by way of contrast, spread through a large number of informants. Neither is endorsed by official channels of information (Coady 2012; Shibutani 1966). In other words, they exist outside the circuits of professional guidance and it is precisely this perceived separation from official knowledge that is valued. For the sake of brevity, I refer to both gossip and rumour as ‘maternal talk’.

### **Theorising Maternal Talk**

My interest in maternal talk has been influenced by anthropological and sociological theories. In 1963, anthropologist Max Gluckman drew attention to the social functions of gossip, arguing that it is ‘part of the very blood and tissue’ (Gluckman 1963, 308) of community life. While subsequent theorists (Paine 1967) went on to criticise Gluckman’s functionalist focus on the maintenance of group values and unity, his observation that ‘gossip is not idle’ (Gluckman 1963, 312) remains convincing.

Sociologist Tamotsu Shibutani provided an influential definition of rumour as ‘a form of communication through which men caught together in an ambiguous situation attempt to construct a meaningful interpretation of it by pooling their intellectual resources’ (1966, 17). His view that rumours emerge when individuals try to comprehend ambiguous situations by filling gaps in their knowledge is especially relevant; the contexts of ‘sudden crises, sustained tension, impending decisions’ (Shibutani 1966, 27) in which he suggests rumours flourish are all apt descriptions of the situation mothers face as they search for a suitable school for their children diagnosed with autism. More recently, the political possibilities of rumour as a form of counter-hegemonic discourse offering an informal outlet for collective criticism have gained prominence (Feldman-Savelsburg, Ndonko, and Schmidt-Ehry 2000; Samper 2002; Scheper-Hughes 1996; White 1994). Maternal talk, I argue, may sometimes be seen as a tactic of resistance to the official claims of medical, therapeutic and education experts.

Sociologists of education have been pivotal in understanding the importance of the parental ‘grapevine’ in shaping school choice. In Britain, Bell and Ribbens (1994) argued that a school’s reputation, largely dependent on informal chat between parents within local networks,

is critical to enrolment decisions. Ball and Vincent (1998) extended the argument, suggesting that this 'hot' knowledge is valued above the 'cold' knowledge produced and disseminated by schools and education authorities. Indeed, this locally embedded hot knowledge is often seen as more reliable than official sources precisely because it is based on direct experience and affective responses. In the Australian context, Dockett and Perry (2007, 87) have also found that parents' social networks provide substantial information that is often considered more reliable in relation to school choice.

A further contribution of the sociology of education to the following analysis is recognition of the ways in which dominant moral discourses of maternal responsibility feed into schooling decisions (Vincent, Ball, and Braun 2010). The struggle to achieve an identity as a good mother is played out in narratives of school choice and school placement. Maternal talk, and reflecting on that talk, is thus a form of pragmatic knowledge and a potent marker of maternal identity.

More broadly, the importance of social networks to women, along with the high value placed on experiential knowledge, has been repeatedly demonstrated in feminist sociology. Although mothers are often thought of as isolated in the home, the patterned dimension of their frequent social contacts with other mothers has been documented in Australia (Everingham 1994; Wearing 1984) and elsewhere (Bell and Ribbens 1994; Litt 2000; Miller 2005; Urwin 1985). Rumour about schools and advice about the education system travels through the largely female world of these localised networks. When women have children with disabilities, including autism, the knowledge and the reflections offered by these maternal networks become critical in much educational decision-making.

Previous sociological analysis, using Californian data, has provided evidence of the extent to which information about autism flows through interpersonal networks increasing the probability of diagnosis (Liu, King, and Bearman 2010). Similar mechanisms are at work in Australia. Informal networks between mothers of children diagnosed with autism are initially built up around neighbourhoods, early intervention centres, support groups and schools. Because the field of autism therapies and autism interventions is characterised by competing claims and controversy, mothers often use the advice of other mothers in their efforts to choose therapies or access services. Driven by the dynamics of hope, especially in the preschool years, many families are willing to try a bewildering and often expensive array of rumoured treatments.

Professional bodies often make strenuous efforts to hierarchically order these various therapies, placing scientifically validated, evidence-based interventions at the pinnacle.

Ultimately, however, in their efforts to remediate their child's perceived deficits, many parents are willing to experiment (Lilley 2011b). In this situation, the autism grapevine, largely based around oral interchanges, is a crucial source of information, advice and warning which supplements and, on occasion, challenges professional guidance.

### **Navigating the Autism Education Landscape**

Autism is a developmental disorder characterised by qualitative impairments in social interaction and communication, often accompanied by restricted and stereotyped patterns of behaviour. Autism diagnosis has expanded rapidly over the past few decades with commentators suggesting various explanations for this apparent developmental epidemic, ranging from neurological insults caused by vaccines or environmental toxins to the effects of expansion in diagnostic criteria combined with diagnostic substitution (Grinker 2008; Eyal et al. 2010; Liu, King, and Bearman 2010). Prevalence is currently being estimated at up to 1 in 88 children, with boys being far more frequently diagnosed than girls (Centers for Disease Control and Prevention 2012).

Correspondingly, school students are now much more frequently identified with autism. In NSW, for example, between 2005 and 2010, there was a 165% increase in the number of public school students diagnosed with autism (NSW Parliament 2012, 12 – 13). Because the disorder is so heterogeneous, the support needs of these students vary widely (Jordan 2008, 11).

In NSW, there are mainstream (regular classes with varying assistance levels) and segregated (support/satellite classes within the grounds of mainstream schools or separate special schools) schooling options for students with a diagnosed disability, including autism. Both mainstream and segregated options are available in the government, Catholic and Independent sectors of the education market.

In the Catholic sector, children with disabilities may receive additional support within mainstream schools or attend one of seven special schools. Support classes are not part of the Catholic Education system. However, the Diocese of Broken Bay has two Independent special schools, one of which has an associated satellite class located within a mainstream Catholic school.

In the Independent sector by far the largest education provider to children diagnosed with autism is Autism Spectrum Australia or Aspect. This organisation has eight autism-specific independent schools in NSW, and nearly 100 satellite classes located in mainstream schools in both the government and the Catholic sectors. Approximately 1000 students are enrolled in these



special schools and classes ([https://www. autismspectrum.org.au/school/aspect-schools](https://www.autismspectrum.org.au/school/aspect-schools), Accessed March 18, 2014). Separate to the Aspect system, the Independent sector also includes a number of multicategorical special schools and two autism-specific special schools.

The vast majority (approximately 75%) of students with disability are enrolled in the government school sector (Powazuk 2013). Since 1990, all children are entitled to enrol in their local government school. This legislation is part of a broader shift towards education policies that support the inclusion of individuals with disability, largely on social justice grounds (Graham and Sweller 2011; NSW Parliament 2012).

A 2012 government inquiry into transition supports for students with complex needs in NSW found that the provision of support ‘is fragmented and complex’ with parents struggling ‘to navigate their way around such a disjointed system’. Similar issues were raised in a 2011 NSW Ombudsman report, which reported that families of children with disabilities had difficulty accessing basic information about the school system and eligibility for services and supports. As one disability advocacy organisation described it, families tend to ‘stumble upon information in *ad-hoc* ways such as through a recommendation from a friend, an internet search or by happening upon a service or individual that could guide them in the right direction’ (NSW Parliament 2012, 28).

Research repeatedly demonstrates that Australian mothers, especially during their children’s primary years, are primarily responsible for undertaking the parental labour of school choice (Aitchison 2006; Campbell, Proctor, and Sherrington 2009). Maternal involvement in transition to school is usually heightened in the case of families with children diagnosed with autism (Lilley 2013a). This is part of a broader international pattern of expectations of more intensive mothering when children are identified with developmental disabilities (Wilkinson 1996, 316).

Rumour, as Shibutani (1966, 41) theorised, ‘constitutes the basis for maintaining a working orientation toward a changing environment’. Faced with opaque education processes, including frequent bureaucratic reorganisation of funding mechanisms and disability provision, mothers of children diagnosed with autism often ask other women who are part of their networks for advice about primary schools.

## **The Research Study**

This article analyses maternal talk or ‘grapevining’ (Ball and Vincent 1998) from a data set of 62 semi-structured interviews with 22 mothers negotiating primary school enrolment for their children diagnosed with autism in Sydney, New South Wales.

As ecological models have noted, transition to school is a process that occurs over time and across varied contexts (Dockett and Perry 2007, 187). In order to capture elements of that process, multiple research interviews were conducted with mothers whose children diagnosed with autism were entering a variety of educational settings including special schools, support classes and regular classes. Participants were recruited through early intervention providers, support groups and Autism Spectrum Australia. All had children with a diagnosis of an Autism Spectrum Disorder who were starting primary school in 2010.

Twenty-two mothers participated in the first round of interviews conducted in 2009 just before their children started primary school, 21 were interviewed in 2010 when their children had almost completed their first year of school and 19 participated in the final interview round in 2011. This qualitative and longitudinal design produced rich accounts of biographical experience (Riessman 2008, 26) across the primary school transition period as mothers tried to make sense of an array of professional guidance and lay knowledge.

On a number of indicators, the mothers were a diverse group. They ranged in age from 29 to 48 years. While the majority (15) identified as Anglo-Australian, 4 had European backgrounds (3 identified as Australian-Italian), 1 was South African, 1 Lebanese and 1 Vietnamese. Most of the mothers were well educated (four had postgraduate qualifications, nine had university degrees and five vocational qualifications). The remainder had more limited education with one having finished and two never completing secondary school. Four women stated that they were struggling financially, 13 described their financial situation as adequate and the remainder said they were financially comfortable. Eleven mothers were not working. Some had previously been employed in highly paid and prestigious occupations (such as medicine), but stated that the care needs of their child required them to stay at home. The remaining 11 women worked part-time. Most were married; however, by the end of the research period, three were single mothers. Three disclosed psychiatric diagnoses of either them- selves or their child’s father.

All interviews, which lasted on average one hour, were recorded. I carried a schedule of the issues to be covered, which mothers were sent in advance. Following the methods of narrative interviewing (Riessman 2008), I aimed to ask questions that opened topics up and to

follow the lead of participants. Mothers, on the whole, welcomed the opportunity to recount some of the difficulties and achievements of the primary school transition period to a sympathetic listener. Before the first interview, I informed the participants that I, too, am the mother of a child diagnosed with autism. This disclosure inevitably shaped the interview encounter and how experiences were narrated; mothers knew I was familiar with many of the dilemmas and difficulties they faced and this shared positioning generally facilitated intimacy and trust (Finch 1993; Miller 1998, 2005). All of these women experienced the diagnosis of their child as a profound biographical disruption (Lilley 2011a; Voysey Paun 2006, 208). In such circumstances, the impulse to make sense of events through storytelling is especially strong (Riessman 2008, 10). Topics discussed included experiences of diagnosis, early intervention, processes of school placement and experiences with schooling. The full set of 62 interviews were transcribed and sent to participants for checking.

The principal method used in this study is thematic narrative analysis. In an effort to preserve individual agency and intention, extended accounts have been preserved and treated analytically as units. This approach differs from grounded theory, which more readily fractures data (Riessman 2008). Smith and Sparkes (2008) draw attention to the growth of narrative forms of inquiry within disability studies. Other scholars, too, have undertaken an analysis of narratives focusing on parental experiences of autism (Gray 2001; Solomon and Lawlor 2013). In its most general form, narrative analysis ‘turns a story told into a story to be formally analysed, extrapolates some sort of theoretical propositions from it and transfers these results by telling them in the form of a realist tale’ (Smith and Sparkes 2008, 21).

The researcher made a summary of each interview while listening to the audio recording. A list of themes was then made after rereading each summary. A full transcription of each interview was also made. These, too, were checked for any themes omitted in the summary. Rumour and gossip emerged as salient themes in this process of checking and rechecking the data set. A decision was, therefore, made to analyse this topic, based on the emergence of maternal talk as a salient theme across multiple interviews. Following this, the transcripts of all the interviews were reread while explicitly searching for relevant material. These segments of the data were extracted, making sure that the context of the rumour narrative was preserved intact. These narratives were then analysed in more detail for emergent themes and patterns.

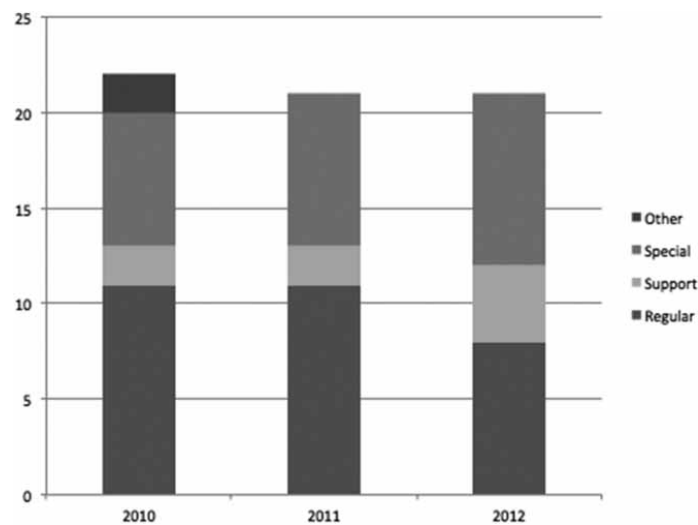
## School Choice and School Placement

A previously reported finding from this overall study is that although official rhetoric in NSW is pervaded by the language of ‘choice’, in reality students with significant support needs are still generally ‘placed’ by professionals in segregated classrooms or schools (Lilley 2014). For mothers, compliance with professional guidance is often equated with responsible, safe behaviour and a realist apprehension of the extent of their child’s needs (Lilley 2012). The presence of both segregated and main- stream education and the substantial arguments surrounding the politics of inclusion vs. the perceived advantages of specialist provision make this maternal ‘choice’ profoundly risky – the well-being of their children and their identity as good and competent mothers is at stake.

The mothers who participated in this study had children (18 boys and 4 girls) positioned across the autism spectrum. Seven were diagnosed with autism and a moderate-to-severe intellectual disability; six were described as ‘borderline’; nine as high-functioning autism (eight) or Asperger’s (one).

Of the 22 women interviewed in 2010, 11 enrolled their children in regular and 9 in segregated settings (2 in support classes and 7 in special schools) for their first year of primary schooling. One woman was home-schooling and another, dissatisfied with the options available, had not enrolled her son anywhere. Of the 21 women interviewed in 2011, 11 had enrolled their children in regular and 10 in segregated settings (2 in support classes and 8 in special schools). In 2012, 8 were in regular classes and 13 in segregated settings (4 in support classes and 9 in special schools) (Figure 7.1).

There are two patterns to note. The first is frequent changes in primary school setting as professionals and parents sought for a better ‘match’ for each child’s needs. These changes indicate the difficulty of finding a suitable setting for some of these children. In these cases, mothers felt intense pressure to find an environment in which their child could learn and be reasonably contented. Primary school choice is not a single definitive event. Families of children diagnosed with autism may need to repeatedly engage in this process. Second, despite the commitment to inclusive education in current Australian policy (Carrington et al. 2012; Cologon 2013), including the legal obligation to give students with disability the right to participate in education on the same basis as students without disability enshrined in the *Disability Standards for Education* 2005, there was a clear trend towards increasing segregation.



*Figure 7.1. Classrooms attended at the beginning of each school year.*

All of these mothers supported the notion of a wide and flexible range of educational provision for their children. In doing so, they often referred to the heterogeneity of children diagnosed with autism and the broad range of difficulties and abilities encompassed within the autism spectrum. Following the distinction drawn by Ravet (2011), it is useful to categorise their responses to the issue of inclusive education in terms of a contrast between rights and needs-based perspectives. Most of these mothers acknowledged a rights-based perspective on inclusive education (though a few had never heard of or thought about this debate) but insisted on the wisdom of adopting a needs-based approach.

Common reservations about placing children diagnosed with autism in regular classes are inadequate resources and an inability to deal with the anxieties or behaviour difficulties frequently found among these students. As argued elsewhere, schools in NSW often mobilise these reservations in their efforts to exclude children diagnosed with autism (Lilley 2013a). Mothers are, therefore, making, or agreeing to, enrolment decisions in an embattled context as they face an arsenal of stigmatising practices, including stereotyping, the claim of insufficient resources and explicit encouragement to try other schools or segments of the education market (Lilley 2013a; NSW Parliament 2012, 48). Given this situation, the diffusion of information about autism education is highly reliant on parents' social networks, often forged through shared experiences of early intervention or autism support groups.

In the following, I analyse mothers' stories about other stories – the rumours and gossip they have heard about schools and classrooms and about how different education settings will deal with their children diagnosed with autism. Pseudonyms for mothers, children and specific schools are used throughout and some biographical details have been altered to protect the anonymity of participants.

### **The Maternal Autism Grapevine**

Mothers participating in this study frequently referred to both gossip and rumour as influencing their views about primary schooling. Mostly this lay knowledge was exchanged orally, but email and Facebook were also channels through which information flowed. For mothers, the important distinction was less the size of the autism grapevine they participated in than the fact that the information available within it was perceived to be qualitatively different to official advice and recommendations. While professionals often dismiss maternal talk as inaccurate and even alarmist, mothers feel they are not being given the whole story and rely heavily on this local knowledge when negotiating primary school enrolments for children diagnosed with autism.

The influence of gossip and rumours about primary school enrolment for children diagnosed with autism was mentioned in 40 of the 62 interviews. Reference to these lay sources of knowledge was most frequent in the first interview (18 out of 22 mothers) in response to probing about how mothers either decided on particular schooling options or came to terms with the placement decisions of professionals. The topic was of less salience (8 out of 21) in the second interview as mothers talked about their children's first year of school. It resurfaced in the third interview (14 out of 19) as women either reflected back on their experiences over time or were engaged in the difficult process of moving their child to another school.

Initially, I suspected that rumours about schools and schooling tended to have a conservative function of pushing mothers towards more segregated options for their children diagnosed with autism. However, analysis of the data points to great diversity in the ways maternal talk either propels families towards or away from inclusive schooling. Listening to and telling these stories is one way in which mothers make sense of their situation. Weighing up the competing claims of maternal talk in relation to primary school enrolment for children diagnosed with autism is crucial in the process of decision-making over time.

As previously noted, maternal talk was mentioned in approximately two-thirds of the interviews. Of the 22 women interviewed, 9 offered more extended commentaries on how rumour and gossip influenced their decision-making. In this section, I analyse these lengthier extracts in order to gauge the uses to which the autism grapevine is put in the context of primary school transition for children diagnosed with autism.

The most common use of the autism grapevine was in supplementing information about the potential suitability of schools and settings. Three mothers specifically mentioned the importance of the grapevine in providing reassurance that they had made the best decision about initial primary school choice. For example, Gaby decided to enrol her son in a support class after attending a support group meeting for parents of children diagnosed with autism: ‘I actually went to my first support group sort of meeting last night and they suggested it – which was better than what Aspect were telling me really because it was real people’s experiences of school.’ This mother clearly distinguishes between professional guidance and parental advice, finding the latter more reliable both because of the commonality of experience shared and the presumed autonomy of parents from official positions and interests.

Mothers also rely on other mothers as a source of information about which schools and sectors to avoid. Phoebe, whose son attends a Catholic primary school, rejected their local government school after hearing a ‘horror story’ about it. This story was told to her by another mother whose child diagnosed with autism and intellectual disability attends a support class in their neighbourhood school:

The local public school wasn’t really an option because I’d heard horror stories about it ... There were several incidents at Sharpstreet Public where there was bullying going on, quite severe bullying, and her oldest son actually got dragged into the toilets and some older girls cut his hair. They pinned him down. It was a really serious incident at the time ... But, yeah, she said it was horrible. It was absolutely horrible, because she said ‘just say he got stabbed with the scissors, or anything could have happened because he was thrashing around’. But that pretty much made my mind up. If he’s going to a public school it will not be Sharpstreet.

Here, we see the full force of maternal talk in narrating an incident of bullying a child diagnosed with autism that school authorities would undoubtedly have preferred to keep quiet.

For some, the advice of other mothers is critical in their decision to try a mainstream school. This subset all perceived their children as ‘high functioning’. Natalie explained that the example provided by a well-known activist autism mother who sent her son to a mainstream school was crucial in her decision to enrol her son at their local government school: ‘So I just planted that in my head and went, “I can do that.”’ Because autism is such a heterogeneous condition, mothers gravitate towards other mothers whose children might be broadly conceived of as similar. Phoebe told me that talking to other mothers whose children were also labelled high functioning informed her decision to enrol her son in a mainstream school:

A lot of them say you don’t want them to be at a school copying kids that are lower functioning. You want them to be at least copying children that are neurotypical if possible. So I took all that on board in my decision.

Hope was not part of an autism grapevine. However, she was part of an active community of neighbourhood mothers who met together at local parks and in each other’s homes on a regular basis. She used this local mothers’ network for information and support in successfully challenging the attempted exclusion of her son from their local government school (Lilley 2013a).

Maternal talk can also lead mothers to either remain in or seek segregated education settings for their child. Felicity repeated cautionary tales of other parents who had donated substantial sums of money to prestigious Independent schools and still been refused enrolment, as well as negative stories that emerged in the context of disability and education information evenings – ‘You know, the principal of my son’s school doesn’t understand autism; my son wants to commit suicide because he is bullied every day.’ These confirmed her view that it is best to keep her children in a special school. For Gaby, the extremely positive response of another mother to an Aspect open day – ‘She raved about it’ – prompted her to move her son from a support class to an autism-specific special school.

Natalie spoke about some of the ‘horror stories’ she had heard through her local autism support group. She cited accounts of the frequent suspension and expulsion of children diagnosed with autism, also reported on in the media (Patty 2012), and the reliance on mothers to remove children during the school day if they are perceived to be causing difficulties. Over the two years, her son was enrolled in his local government school, she reported constant battles to have him adequately supported. Despite paying approximately A\$20,000 per annum to fund



her own therapists to support him throughout the school day, she still felt that the school was inflexible about accommodations and even hostile to her advocacy efforts. Shortly afterwards, she moved her son from a mainstream school to a support class. In this case, maternal talk confirmed Natalie's misgivings and provided a broader confirmation of some of the difficulties children diagnosed with autism and their families sometimes experience in mainstream schools.

For others, maternal talk provided confirmation that they had made the right choice or were being offered a suitable placement when changing schools. These examples involved a move from mainstream to segregated provision, and were revealed in the third interview. Melissa's son was initially enrolled in his local government school. He was then moved to an autism-specific support class and, from there, to an autism-specific special school. These repeated moves to more segregated settings worried her. Seeking further information she rang another mother whose son attended the special school. Melissa perceived this reassuring information as qualitatively different from that provided by professionals. Mothers can be relied on to tell 'what it's like, warts and all'. Sally also relied on information from another mother when she moved her son from a mainstream to a special school. She emailed her friend, asking 'pointed questions', such as 'Is it a mainstream syllabus or is it a holiday camp?' Reassured that she would not be setting her son up 'to fail throughout his life by not keeping up', she proceeded with the new enrolment.

### **Maternal Reflections**

The previous section focused on the diverse ways in which mothers of children diagnosed with autism make use of 'hot knowledge' about schools, often acquired through maternal networks. Participation in these networks can be forged through shared early intervention experiences, use of social media (such as Facebook) and/or attendance at autism support groups. When students are enrolled in either a support class or a special school, mothers are especially likely to maintain contact with one another, either when children are collected in the afternoons or through social activities such as fundraising events or mothers' dinners.

When mothers of children diagnosed with autism talk to one another, they do not only pass on relevant information. They also model themselves via the attitudes and actions of other mothers. Research in feminist sociology has highlighted the important role of interpersonal networks in building maternal identity (Bell and Ribbens 1994; Litt 2000). As mothers of children diagnosed with autism, women often struggle with their own stigmatised identity

(Lilley 2013b). Autism diagnosis radically calls into question the usually accepted scripts for childrearing and expected trajectories of development. Through talk with others who share their experience, these women negotiate definitions of what is and what is not appropriate or possible for their children, including decisions about education.

Gossip and rumour are, as White (1994, 79) has noted, 'idioms of intimacy'. Mothers of children diagnosed with autism are generally drawn together as they face similar difficulties and challenges along the timeline of their caring. Following diagnosis, access to early intervention is the first major issue substantially informed by the autism grapevine. School enrolment and services are the next. A spirit of camaraderie and mutual assistance usually characterises these interactions. As one mother put it to me, 'Everyone is in the same boat to a degree, and there are things that I know about that I can tell other mothers about and they can tell me about things that I don't know about.' Some mothers were critical of women's perceived tendencies to gossip ('I'm not kidding myself; I know what other women are like') and attempted to distance themselves from the potentially judgemental maternal gaze of others ('Sometimes I think we can get a bit too much oestrogen in one room, if you know what I mean').

But all saw maternal grapevines as offering a particular kind of knowledge based on experience and a specific affective concern with how services and classrooms concretely enact their business on a day-to-day basis (Ravet 2011, 668). Mothers highlighted their emotional connection with their child and the ways in which this allowed them to make decisions that are truly in their interests, even when this conflicted with professional guidance. Carmella, for instance, defended her decision to send her son to a different special school than that recommended by his special educator, explaining 'She only has him at the preschool; I have him emotionally at home.'

Women repeatedly told me that they were concerned for the 'happiness' of their son or daughter, and they found that other mothers were the best source of information about whether their child might be contented in a particular classroom or school. In other words, they were very concerned with the 'feel' of different education settings with many looking for what one mother explicitly described to me as 'the love'. This emphasis on the welfare aspect of schools was strongest among mothers whose children were also diagnosed with intellectual disability. Many of these mothers believed that segregated settings were more likely to offer protection and genuine care to their vulnerable children (Lilley 2012).

Long-term goal orientations stressing academic achievement and future careers were rarely mentioned and only by those whose children were described as high functioning. Even in these cases, this hopeful frame tended to become increasingly circumscribed over time. Put differently, school ‘choice’ for mothers of children diagnosed with autism is usually not a strategy of social and economic reproduction. Aspirations are generally reframed to primarily reflect a concern with emotional well-being (Ball 1997; Ball and Vincent 1998). As Bagley and Woods (1998, 780) expressed it, in relation to parents of children with special educational needs in Britain, ‘school is not viewed fundamentally in an instrumental perspective: the end or outcomes of schooling are immanent in the experience of schooling’.

Feminist theorists have pointed to the ways in which the child-centred networks of mothers constitute a ‘moral community’, observing and commenting on the beliefs and practices of other mothers. This may be perceived as a form of support and cooperation. Equally, it might be felt as competitive and judgmental. But all come to experience their particular situation through a process of comparison and contrast with others. Bell and Ribbens (1994, 233) succinctly describe this complex process of (dis)identification as creating the ‘looking glass family’. Mothers are very attuned to the vast differences in abilities and talents between children diagnosed with autism and are engaged in constantly trying to accurately ‘place’ their own child (Lilley 2011a). These reflections and the usually fraught ‘sorting’ that follows are critical in shaping maternal attitudes to inclusive schooling.

Joanna, for example, explained why she supported a ‘continuum of placements’ even though her son is enrolled in a mainstream school.

If I had a kid further down the spectrum I would much prefer them to be in a satellite class with five other students. I’ve got a friend who’s in that situation with her son. He couldn’t cope; they sent him off to mainstream school and he was . . . it was diabolical – so sad for him, horrible for the other students, impossible for the teachers. He’s happy now. He’s in a place where he can be part of it; he’s got the best of both worlds. I think there’s room for everything.

When mothers of children diagnosed with autism listen to the advice of other mothers they are more likely to be influenced by those whose children are placed by experts at a similar point on the spectrum. There is a vast gulf between the needs of those considered high functioning and those with intellectual disability. This gulf is overtly acknowledged by mothers, sometimes

with sadness, as they make remarks such as ‘I think her little girl is a little bit more advanced than my son.’ It is these distinctions that allow an assessment of the relevance of maternal talk about schools to one’s own situation. These maternal reflections are part of being, and being seen to be, a responsible and good mother (Lilley 2013b).

It is important to note here that while mothers clearly distinguish between professional guidance and maternal talk, the division between experts and parents is often blurred. Eight of the 22 mothers interviewed stressed their professional expertise in relation to their child. Three of these women were qualified teachers, two were medical professionals, one was a lawyer and two had previously worked in the disability sector. Also mothers often pay particularly close attention to the advice of female professionals who are part of their friendship networks. These special contacts are valued either because they are perceived to have access to confidential information (Shibutani 1966, 14) or because they straddle maternal and professional worlds and are thereby viewed as having greater insight.

Participants often mentioned the importance of advice from female friends who are teachers in either confirming school enrolment decisions or in warning them against particular schools or sectors of the education market. When these women also had a child with a disability, their opinions carried extra weight. One mother, for example, told me that she did not consider a nearby school because of the negative experiences of a mother she initially met through her son’s preschool. This friend has an older daughter who is a ‘selective mute’ and a son ‘with high-functioning autism’. ‘Her mum is so angry with the school about the special needs side of things’, Joanna explained, ‘she’s taking her out this year, and her daughter and her son are going to another school’. ‘And she’s a teacher herself’, she added, indicating that this insider perspective made her judgment even more reliable.

Maternal talk was important to most of these mothers, either as a source of novel information or as a confirmation that they were taking the best course of action possible given the constraints of their circumstances. When mothers valued the advice of other mothers, it was primarily because they were seen as having the same perspective derived from sharing similar experiences. That perspective was represented as generating a focus on the happiness and well-being of individual children against the potential inconsistencies and inadequacies of the education system. This twin marshalling of affect and experience underpins membership in the moral community of ‘autism Mums’, wherever their children are located on the spectrum.

## Conclusion

For mothers of children diagnosed with autism, the period of transition to primary school is characterised by active engagements with professional guidance (Lilley 2014) and grapevine knowledge about the pros and cons of various schools and market segments. Much of this grapevine knowledge circulates among mothers as they carefully weigh the available options for their child. Mothers critically assess both rumours and expert advice as they engage in the substantial labour of researching school choice and school placement. Sometimes, maternal talk pushes mothers towards segregated settings; at other times, it encourages them to pursue mainstream enrolment. The stories they tell about school choice are frequently ambivalent and, to borrow a term from Ball (1997, 4), ‘fuzzy’, sometimes disrupting dichotomies of expert vs. lay knowledge or implicitly querying the relevance of taking a set position on inclusive education.

As Ravet (2011, 679) has cogently argued: ‘Neither the rights-based perspective nor the needs-based perspective has a monopoly on the values of social justice.’ Mothers are focused on their particular child and situation. Maternal narratives resist totalising perspectives on autism and education and refuse entrenched positions on special education vs. inclusive education. As their children grow older and as they encounter different classrooms and schools, these women revise their opinions and attitudes. This fluidity is required by circumstances, allowing for developmental change and for alterations in education provision and funding. Maternal talk provides a resource for comparison with like and unlike others; within the multiple twists and turns of this grapevine, mothers can generally find support and confirmation that whatever decision they have made, or accepted, at a particular point in time is in the best interests of their child. Whether this hot knowledge is accepted or rejected, sought out or ignored, it has potency precisely because it is intimate, experiential and unofficial.

Coady (2012, 102) has argued that the unofficial nature of rumours provides a salutary check on institutional power and attempts to control and limit information. This study confirms his argument. The ‘horror stories’ mothers tell each other – of inadequate resources, bullying, attempts at educational exclusion, or the incompetence or callousness of educators – cannot be found in policy statements or school prospectuses. In conveying these stories of injustice, women make a claim to be heard. When we listen to them, we hear justified anxieties about their children’s future, staunch criticisms of education provision for students with autism in NSW and a clear demand for social justice.

Paraphrasing Shibutani's (1966, 37) insights into rumour, we can say that although the temporal reference of maternal talk may be to the future ('there is a new autism support class opening soon over there'; 'all the funding criteria for disability are about to change') or to the past ('look at the terrible thing that happened to her child in that school'), the subject matter always has present significance. 'Events of the past and future', he argues, 'are of concern because of some decision that has to be made at once'. Mothers of children diagnosed with autism who are transitioning to primary school are frequently faced with difficult decisions about which school or classroom will be in the best interests of their child. In making that decision, they listen to other mothers. By participating in the autism grapevine, they gain pragmatic experiential knowledge, which informs their choice or their willingness to accept education placements as advised by professionals. In the process, they also constitute themselves as members of a moral community, creating and consolidating their imagined identity as 'autism Mums' through the refractions, sometimes alarming and sometimes reassuring, of other mothers.

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## **Chapter 8**

### **Publication #6**

#### **Trading Places: Autism Inclusion Disorder and School Change**

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## Trading Places: Autism Inclusion Disorder and School Change

This article investigates the experiences of students diagnosed with autism who change schools during the early primary years in New South Wales (NSW), Australia. Using the narratives of eight mothers, the article documents the circumstances leading to school change, usually towards more segregated provision. Mothers highlighted the difficulty of these school transitions and the family distress that often prompted change. The eight cases of school change that are analysed provide a stark picture of the extent to which Australian schools are unable to adapt to these students. Rather than searching for the causes of these difficulties in the behaviour of students, it is argued that we need to look at the pattern of deficits found in classrooms and schools, as described by concerned mothers. In this article the pattern is referred to as Autism Inclusion Disorder. The defining features of this disorder are the co-presence of persistent school deficits in social communication/interaction (including teacher inability to interact with students) and school restricted and repetitive behaviours (such as rigid adherence to negative behaviour management). Maternal school change narratives suggest that for a genuinely inclusive education system to develop more attention should be directed towards changing schools rather than changing children to fit traditional classrooms.

**Keywords:** disability; autism; mothers; inclusive education; special education; school change

### Introduction

When autism was first perceived as a potential diagnostic entity by psychiatrist Leo Kanner in 1943 it was believed to be a rare condition (Eyal et al. 2010). Nowadays, due at least in part to changes in diagnostic criteria, autism has become a much more frequently identified neurodevelopmental disorder with at least one in 160 Australian children between the ages of 6 and 12 being placed ‘on the spectrum’ (Roth 2013). Currently, a diagnosis of autism is based on deficits in social communication and social interaction, as well as the presence of restricted repetitive behaviours, interests and activities. These symptoms must begin in early childhood and cause significant functional impairment, usually across the lifespan (Hyman 2013).

Australian policy has followed broader international shifts in the education of all children with disabilities, including autism, promoting a presumption of inclusion. As numerous commentators have noted, however, there is a substantial gap between the rhetoric of inclusive education and everyday bureaucratic and classroom practice (e.g. Cologon 2013; Graham and Spandagou 2011; Lilley 2013; Slee 2011). In New South Wales (NSW), Australia’s largest state,

students continue to be subjects of elaborate systems of classification, sorting them into differential tracks according to perceived potential as they are manoeuvred around tiered systems of schooling, with those thought of as less able or more difficult directed towards segregated settings.

On paper, all students diagnosed with autism (SDWA) in NSW are entitled to attend their local school. In practice, these children usually remain in a mainstream classroom only if they meet similar expectations of academic performance to their peers and, more importantly, follow norms for appropriate classroom conduct. Segregated schooling, either 'special' schools or support classes, continues to be used to manage and exclude children considered too troublesome, difficult and/or impaired. The benign face of this differentiated education system is a concern with the 'best interests' of students with disabilities. The provision of segregated education offering more intensive resources, particularly specialised teaching and smaller classroom sizes, continues to be seen as preferable for some students.

The focus of the bureaucratic management of the differences presented by SDWA is to concentrate on treating, containing and channelling the deficient child. In the following, I propose to reverse this procedure by focusing, instead, on the deficiencies of schools and classrooms. These deficiencies are described in maternal accounts of how schools and classrooms in NSW, both mainstream and segregated, often struggle to effectively include SDWA. Mothers also spoke about the family suffering that these systemic school failures produce. What characteristics of school deficiency, I ask, lead to these continuing forms of educational exclusion?

In answering this question, I mobilise the diagnostic notion of 'disorder' used in clinical descriptions of autism (and other disabilities). In doing so, I engage in a tradition of parodying medicalised understandings of autism. Advocates in the autism rights or neurodiversity movement use parody to draw attention to the reductions of the clinical gaze. Perhaps, the most famous example of this is the Institute for the Study of the Neurologically Typical webpage (<http://web.archive.org/web/20090119044143/http://isnt.autistics.org>, accessed May 6, 2014). Through such humorous reversals, these parodies encourage a sense of critical distance from clinical perspectives. In the process they make a powerful case for understanding autism as variation rather than pathology.

It is in this spirit that I, too, engage in parody, deploying the construct of disorder to unsettle some common assumptions about SDWA and to suggest we turn our attention away from individual deficits towards institutional deficits. Once we identify the underlying patterns of

everyday practice that make up Autism Inclusion Disorder (AID), I argue, we may be able to begin the task of remediating these ongoing patterns of separation and segregation. Put differently, if we listen attentively and with respect to the narratives of mothers of SDWA who have changed schools, we can start to grasp why it is schools and not students who need to change in order to achieve inclusive education (Cole 2005, 2007; Kluth et al. 2007; Runswick-Cole 2008). This focus on the disabling attitudes and practices of schools is firmly positioned within a disability studies perspective that addresses the cultural and political conditions of disabled people's exclusion (Goodley 2011).

### **Studying School Change for Primary Students Diagnosed with Autism**

This paper draws on material from an in-depth qualitative study investigating the experiences of mothers when their children, diagnosed with autism, were starting primary school in Sydney, the capital of NSW. Twenty-two mothers were interviewed in 2009 when their children were transitioning to primary school the following year; 21 of these mothers were interviewed again one year later; 19 participated in the final interview round in 2011 with another 2 mothers continuing to provide information via email. Mothers were interviewed because they are usually the primary carers of young children and research, both international (e.g. David et al. 1997; Traustadottir 1991; Wilkinson 1996) and Australian (e.g. Aitchison 2006; Campbell, Proctor and Sherington 2009; Lilley 2013), has repeatedly shown that mothers undertake most of the labour involved in school choice as well as taking primary responsibility for ongoing negotiations with educators and other school personnel.

None of the mothers interviewed for this research worked full-time, with all mentioning that the demands of having a young child with a disability made this impossible. Of the 19 participants who provided financial information, 5 said they could meet basic needs, 11 indicated that their position was financially adequate and 3 stated that their families were in good financial condition. The majority had post-school qualifications, including three teachers, a doctor, a nurse, a physiotherapist and a lawyer. Thus, they frequently brought substantial cultural capital to their encounters with educators and other professionals.

Some caution is required here, however. Drawing direct connections between socioeconomic status and levels of maternal advocacy is difficult. The class positioning or, if preferred, level of privilege of mothers of children with disabilities can be remarkably fluid. This is because these mothers are often forced to either limit their position in the paid workforce or

cease working altogether due to their caring responsibilities and the scarcity of social supports (Gray 2002; Porterfield 2002). The mothers with lower educational attainment who participated in this research still actively supported and fought for their children. However, they were less likely to mobilise their own privately funded network of professionals (e.g. psychologists) when contesting school decisions.

The material presented in this article is drawn from the eight cases (24 interviews), where mothers reported that their children had changed schools and this change was not attributable to geographic mobility. Using thematic narrative analysis extended accounts of the sequential circumstances eventually resulting in school change were extracted and treated analytically as units (Riessman 2008). The resulting argument is not intended to make general empirical claims about the circumstances of all SDWA and their families. Rather, this sample provides insight into the contexts within which school change occurs and some of the common characteristics leading to this outcome.

When mothers experience major disruption in the normative school biographies of their children they often develop long and detailed accounts of that disruption and of its emotional impact on their families. My aim was to ask questions or seek clarifications that opened up the issue of school change, allowing in-depth reflection. In doing so, I sometimes acknowledged my own experience of being a mother of a SDWA. My son attended three different school settings during his first four years of primary education. The difficulties of his school career made me a sympathetic listener, aware of many of the hurdles and constraints these women faced when school became a place of repeated frustration and disappointment for them and their children.

In NSW students diagnosed with a disability, including autism, can be enrolled in a regular class in a mainstream school, in a support class located within the grounds of a mainstream school or in a separate 'special' school. The terminology for these placements varies across different sectors of the education market and, for the sake of clarity, I refer throughout to support classes and special schools, with both being categorised as segregated placements. All children have the legal right to attend a regular class at their local government school.

Education professionals usually represent support classes as less segregated or more inclusive placements than special schools. Regular classrooms in mainstream schools are generally seen as the most inclusive option. As many theorists of inclusive education have argued (e.g. Armstrong and Spandagou 2011; Vislie 2003), there is frequent slippage between integration and inclusion. Older ideas of integration, based on assimilating pupils with disability



into existing forms of schooling, remain the norm. Inclusive education, in contrast, requires substantial transformations in policy and practice aimed at ensuring the genuine participation of all diverse learners in common schools and classrooms. Nevertheless, assimilation is often misrepresented as inclusion (Slee 2011).

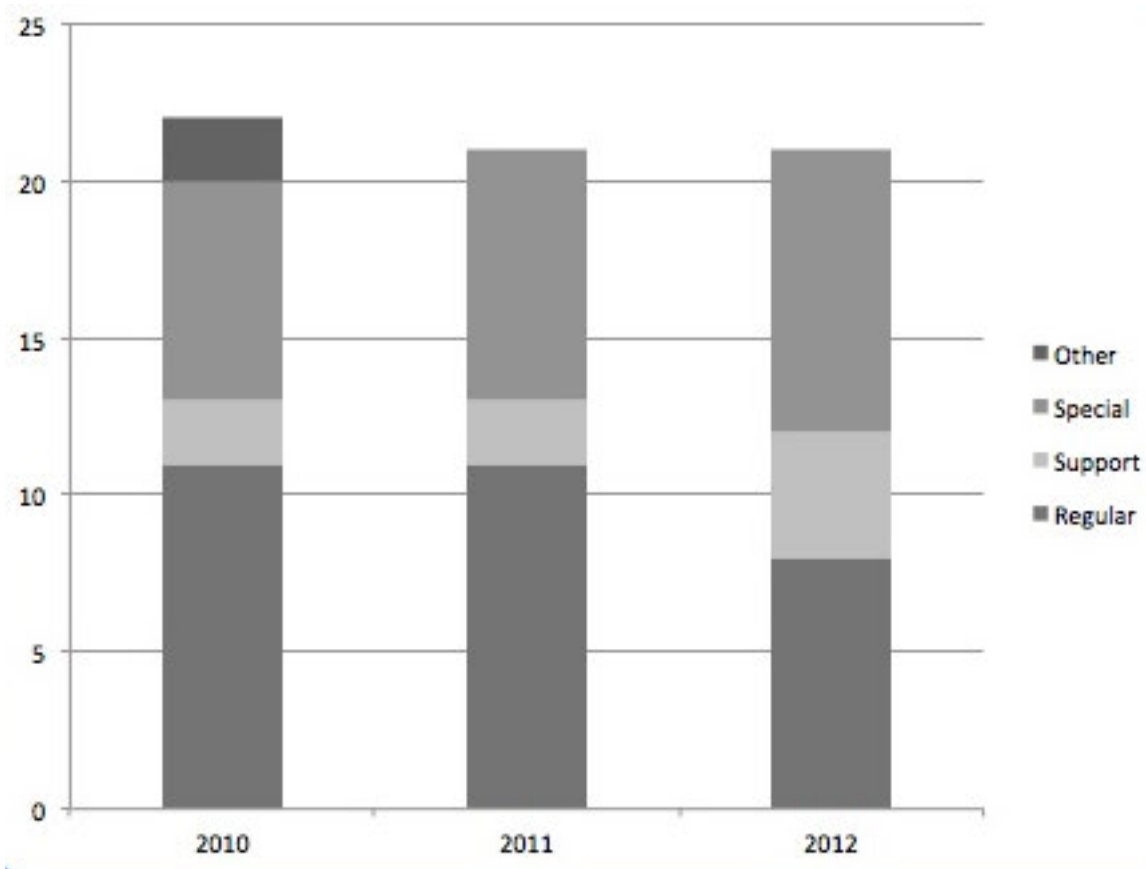
Autism is an extremely heterogeneous disorder and the children of participants in this project reflected that variability. Of the eight students being considered here only one, who moved from an autism-specific special school to a government support class, had a concurrent diagnosis of intellectual disability (ID). Six of the eight children were described by their mothers as either ‘developmentally delayed’ (1), ‘borderline’ (3) or ‘high functioning’ (2) with some flux over time between these labels, which were generally based on scores in psychometric assessments. One had a diagnosis of Asperger’s Disorder. The overall pattern from the larger data set was for students diagnosed with autism spectrum disorder (ASD) and ID to remain in the segregated setting in which they were first enrolled (six of seven). For this sample, it was thus mainly those students categorised as more intellectually able who experienced considerable flux in their enrolments in the first few years of primary school (see Table 1).



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Of the 22 women interviewed in 2010, 11 enrolled their children in regular classes in mainstream schools and 9 in segregated settings (2 in support classes and 7 in special schools), with 2 not yet enrolled anywhere. Of the 21 women interviewed in 2011, 11 had enrolled their children in mainstream and 10 in segregated settings (2 in support classes and 8 in special schools). In 2012, 8 were in mainstream classes and 13 in segregated settings (4 in support classes and 9 in special schools). Only one of these children moved from a segregated to a mainstream setting during the course of this research.



*Figure 8.1: Pattern of primary school enrolments 2010-12 for the entire sample of 22 participants.*

While there are no statistics available regarding the number of primary school enrolment changes for the entire population of students in NSW, the fact that approximately 40 per cent of SDWA in this sample changed schools suggests a very high rate of movement for this group. The data presented here also highlights the great difficulties students and their families were

experiencing in different schools and classrooms. Further, despite the promises of inclusive education, SDWA and ID all remained in segregated settings and, even for those students without a diagnosed intellectual disability, a trend towards increasing segregation is clear.

### ***No Big School Next to the Fire Station: Mothers Initiating School Change***

The eight cases of school change being analysed arose in response to maternal concerns that their child was suffering in their current school. These concerns emerged in both segregated (four) and mainstream (four) education settings. For every family the decision to move schools caused considerable anguish and, usually, intense stress for the SDWA (see Kluth et al. 2007).

Three examples will suffice to broadly illustrate some of these difficulties (pseudonyms are used throughout). Angela moved her son Jarrod from an autism-specific school in the Independent sector to a regular class in a mainstream government school after one year. Over the course of Jarrod's first year, Angela became very concerned because her 'poor suffering child' developed an anxiety disorder, which she attributed to the challenging behaviours of other SDWA in his class, mentioning that he had been 'attacked a few times'. Angela was also concerned that Jarrod, unlike many of his peers, was not transitioned to the less segregated setting of a support class.

Melissa moved Callum from his local government school to autism-specific provision halfway through his first year. In his first months of enrolment, Callum experienced numerous difficulties at his local school. Melissa was especially concerned when he developed Obsessive Compulsive Disorder:

He'd refuse to walk down the stairs; he'd have to crawl everywhere - here, not out, thank god. Everything was routine bound and he'd go berserk if we changed anything and he kept saying, '*no big school next to the fire station*'.

At first Jana was excited when Anthony was transitioned from an autism-specific special school to an autism-specific support class. This move was part of an established policy of transitioning students to 'the least restrictive setting'. However, he was very unsettled in this new setting. Confronted with her son's constant attempts at school refusal, she eventually moved him back to the special school. She spoke of the continuing emotional distress, to both herself and her son, which led to this decision:

He fights me so hard in the morning. In the end I will say to him ‘I’ll put you in the car in your pyjamas and you have to get dressed at school with the teachers’. It just breaks my heart because he’s crying, he’s screaming and I’m getting so depressed because by nine o’clock I’m just so drained, so out of energy I need to just – I’m so spaced out. It’s like I’ve been hit by a bus and I’m still trying to take it all in.

In all eight of these cases, mothers understood themselves to be initiating change as part of their responsibility to act in their child’s best interests. Often these changes involved considerable maternal labour, including the hiring of external experts to confirm the need to act and, sometimes, to advise on the next move. The provision of services to children diagnosed with autism and other developmental disabilities involves a vast network of expertise (Eyal et al. 2010), and mothers proved adept at exploiting the strategic possibilities of this network in order to leverage school change.

Seeking the assistance of expert intermediaries in disputes with educators and school bureaucrats often led to conflict. However, mothers were prepared to be labelled ‘difficult’ if they thought their actions were helping their child (Larson 1998; McKeever and Miller 2004). Indeed, the willingness to engage in these kinds of battles was often presented by mothers as an integral part of their efforts to be good and effective advocates (see Ryan and Runswick-Cole 2009). When, for example, Melissa, a legal professional, began thinking about moving Callum from his local school, she engaged experts (an occupational therapist and a play therapist) to give their ‘independent view’ of the situation. After doing observations, both immediately advised her to ‘get him out’. At this point, a speech therapist suggested Callum would benefit from moving to autism-specific provision.

Mothers engaged experts to assist with school change as part of a more general pattern of tenacity in seeking solutions to their child’s difficulties. The maternal narratives describing the school impairments that led to these untenable situations also positioned the tellers as good mothers, determinedly protecting their children and promoting their interests (Todd and Jones 2003). In fact, mothers sometimes made claims to be more involved or more knowledgeable about autism services than other mothers of SDWA. Thus Jana remarked:

But see the difference between some of these women and me – if there’s something I don’t like I will try to change it while some of them are like ‘Well it’s

okay, it's not major' ... We have worked so hard and we don't accept but the best for our son.

Research has consistently found that mothers of children with disabilities become, of necessity, skilled in negotiating expert networks and securing services (e.g. Cole 2007; McKeever and Miller 2004; O'Brien 2007), thereby developing 'special competence' in their negotiations with professionals (Ryan and Runswick-Cole 2008). Ryan and Runswick-Cole (2009) have documented the enhanced advocacy (and sometimes activist) role of mothers of children diagnosed with ASD. Mothers' advocacy work is partly a response to the pressure exerted on them to conform to traditional ideologies of selfless maternal care, referred to more specifically by Eyal et al. (2010, p.238) as 'the ethical vocation of autism parenting'. Most obviously, this need to advocate is related to a lack of appropriate support and services, as well as the difficulties 'outsiders' can have in understanding or interpreting the behaviour of children experiencing disabilities (Ryan 2008).

### **Resourcing Autism in Schools**

As Slee (2011, p.147) has noted, arguments about resources are at the centre of inclusive education debates. In NSW, recent government inquiries have found that funding for students with disabilities is 'grossly inadequate to enable full participation by these students in the education system' (New South Wales Parliament, Legislative Council, Standing Committee on Social Issues 2012). Mothers interviewed for this study cited concerns about inadequate resourcing for SDWA. Many had gained this impression through various news media; others had heard rumours from relatives or acquaintances; a few were told directly that this would probably be the case by government sector representatives who encouraged them to look elsewhere. For some these concerns led to scepticism about enrolling their child in a regular class; for others it was a salient factor in their decision to choose, or acquiesce to, a segregated placement.

Angela, for example, provided a clear illustration of the strength of this push factor when she explained her decision to initially enrol her high-functioning son in an autism-specific special school:

We know there's no support there for these children [in the mainstream]. We know that if Jarrod was to go in he might be lucky to get a couple of hours a week support. That's not inclusive. It's not because they don't want to, and I know



principals that love this idea, but they just don't have the resources to do what needs to be done.

Jana also enrolled her son in an autism-specific school largely due to resource issues. She made her decision after speaking with a disability consultant from the government sector:

I spoke to a lady from where you do a referral for placement for kids with public schools. Basically the level of support was going to be maybe \$6000 a year or an aide for two hours a week, twice a week or something. It wasn't going to be something substantial.

Those families who opted for mainstream schools were forced to promote a deficit model of their child as part of the battle to extract funding from education bureaucracies. Mothers whose children were enrolled in the government sector reported that, through the mechanism of individual funding meetings, they tried to have their child's support needs assessed as highly as possible (see Graham and Spandagou 2011). Melissa described how her legal training assisted in increasing the severity of her son's classification, which resulted in more funding. 'I'd made him out into this walking time bomb', she explained. Being knowledgeable about the demands of the funding process and acting in the child's best interests by highlighting their perceived deficits is difficult maternal work.

Two of the mothers of SDWA attending government schools were augmenting the resources available either by providing money to help pay for extra paraprofessional assistance or by employing their own staff to work one-on-one with their child at school. Melissa told me that the principal of her son's primary had explicitly suggested that she could 'top up' in order to buy more teacher aide time. Natalie paid for and managed her own team of therapists, trained in the principles of Applied Behaviour Analysis (ABA), to provide almost constant support for her son Evan during the school day. This cost approximately A\$20,000 per annum. This arrangement was a source of continual tension between her and school staff as she expected her private hiring of therapists to give her greater leverage over school decisions impacting on Evan.

These two cases suggest that families with greater financial resources may be in a position to better support inclusive education for their child. Ultimately, however, this discourages systemic change and points to surprising class inequalities in provision for students with disabilities, even in the government education sector.

Sometimes, however, parents are pleasantly surprised by the level of funding for SDWA in mainstream government schools. Usually this funding is used to buy extra aide time, a point we will return to later. Melissa secured A\$14,000 per annum for Callum after she advocated for him in the funding meeting. When Angela moved Jarrod from a special school in the Independent sector to a mainstream government school she found that her son's funding increased substantially after initial behavioural difficulties. Eventually he received nine and a half hours a week of teacher aide time. The school then pooled his funds with those of another student with a disability so that a paraprofessional could assist both of them for most of the day.

Sally, in contrast, remained bitterly disappointed with the resources her son Todd received at a mainstream Independent Anglican school. When she enquired about an Individualised Education Program (IEP) she was told 'we just aren't able to resource that kind of individual program'. A former teacher, Sally questioned the extent to which resources determine the possibility of inclusive education suggesting, instead, that genuine willingness to commit to inclusion is the real issue. 'I think the resources are there', she commented, 'they're just not doing it'.

In the following, I point to some of the factors hindering inclusive schooling in everyday classroom contexts, as well as the ways in which mothers are discouraged from pursuing either less segregated or more inclusive options, as reported by these eight women. Autism, as previously mentioned, is based on a) persistent deficits in social communication and social interaction, and b) the presence of restricted, repetitive behaviours and activities. Maternal narratives point to the presence of these very deficits in educator practices present in both segregated and mainstream classrooms. If we move our gaze from the child to the institutional practices fostering exclusion, we can begin to appreciate the prevalence of AID in schools.

## **Diagnosing Autism Inclusion Disorder**

### **A. Persistent school deficits in social communication/interaction**

Teachers and other school personnel often demonstrated persistent deficits in social communication/interaction across varied contexts. One of the most commonly observed deficits is *an inability to interact with SDWA*. The practice of delegating most of the responsibility for a child's learning to a teaching assistant is a prime example of this deficit.

Reflecting back on the reasons for moving her son from his local government school to a segregated placement, Melissa explained ‘Cal was effectively being taught by the aide, but the teacher had nothing to do with him’. Camilla told me that her son Christos was only being ‘babysat’ at the mainstream Catholic school he attended.

Whenever I sneak in and have a little peek at what’s going on, he’s on the computer by himself, he’s listening to music by himself or he’s just walking around the classroom while they’re sitting down listening to a story or writing in their books.

Sally was concerned because her son Todd was told to leave the room and sit outside whenever he expressed reluctance over a school task. All of these cases illustrate ongoing practices of internal classroom exclusion with little more than token efforts at integration, let alone inclusion.

Teachers and other school personnel may also have severe problems in maintaining relationships. As we have seen, this may include a lack of engagement with SDWA. This lack of engagement can also extend to family members, particularly mothers. A view by teachers of parents as peripheral to their child’s education or even as adversaries has previously been reported in the literature (Stoner et al. 2005). One of the social/communication deficits that has the greatest impact on families is making parents feel unwelcome, including *the exclusion of mothers from classrooms*.

Melissa volunteered to help with reading in her son’s mainstream classroom. Although she knew other mothers of typically developing children who regularly helped out, she was told by the principal to ‘take it easy’. Natalie did help with reading groups but ‘got the cold shoulder from his teacher massively’. Jana complained that parents were deliberately shut out at her son’s autism-specific support class. Parents were instructed that they were not allowed to go into the classroom and that they would only be allowed to volunteer at a different site.

*Difficulties in communicating with families and/or constant negative communications* also form part of the pattern of school deficits. These school communication deficits pose particular problems for families in relation to SDWA because their children are often unable to tell them about school matters or give their own version of classroom events. As Camila put it, ‘if something happens he can’t tell me’.

Mothers whose children attended regular classes in mainstream schools complained that there was ‘no reporting feedback’; that ‘decisions get made without any consultation at all’; that

they were refused meetings with classroom teachers and told that all of their communication had to go through Department of Education representatives and, in some cases, that there was just ‘no communication at all between the school and the parent’.

Sally was upset by ‘constant ongoing negative reports’ in her son’s communication book. At a meeting she initiated to discuss these negative comments, the head of learning support at this mainstream school repeatedly asked her if she had thought about other schools for Todd.

The final frequently reported school social deficit is an *inability to make use of familial knowledge and expertise*. Mothers often remarked that their intimate knowledge of and experience in teaching their child was of little interest to educators who had difficulty incorporating parental suggestions or recognising parental expertise (Cole 2007; Stoner et al. 2007). Mothers spoke specifically of being devalued. Natalie gave a sardonic summation of this attitude in a mainstream school: ‘No one takes me seriously because I’m just the emotional parent. What would I know? And because the teacher doesn’t respect me.’ Jana, whose son attended an autism-specific class, eloquently expressed the wide-ranging educational costs of this inability for all SDWA:

I do apologise for what I’m going to say but I’m sorry – they do not know my child the way I know him. I have been with him for the past seven and a half years. They can benefit from our knowledge. I think we should work together. It shouldn’t be I hand them my child and then they do whatever they want because it doesn’t work that way. They don’t know him. They don’t know how to work with him.

## **B. School restricted and repetitive behaviours**

Alongside the persistent deficits in school social communication/interaction, outlined and illustrated in the preceding section, symptoms of school restricted and repetitive behaviour also need to be present to reach a diagnosis of AID. Two common forms of restricted behaviour are a) *an inability to implement creative strategies for including SDWA* in many school activities (often due to stereotyped understandings of autism) and b) *rigid adherence to negative behaviour management*.

Children were sometimes excluded from aspects of school life due to presumptions about the behaviour and preferences (‘it’s too noisy’ or ‘it’s overwhelming’) of all SDWA. Mothers in

this study often questioned this mythic autism discourse and the automatic assumption of traits leading to marginalisation (see Mehan, Hertweck and Meihls 1986). This mythic discourse, which draws on both popular representation and medicalised deficit models of disability, relies on stereotypes and typifications, wherein individuals diagnosed with autism are seen ‘as generically “odd” or even dangerous’ (Murray 2008, p.9).

Further evidence of restricted and unimaginative practices may be found in the area of behaviour management. While most schools have adopted policies of positive behaviour support, individual teachers may still exhibit a tendency towards punishment and the use of aversives (see Starr and Foy 2012). Natalie echoed the concerns of many mothers when she observed that in her son’s regular classroom ‘everything was punitive’.

Gaby, too, was upset that her son’s Kindergarten support class teacher placed him in ‘time out’ for wetting his pants. She drew attention to the gap between the rhetoric of positive behaviour support and teacher practice:

They told me, before we started at the support class, that their policy was pretty much to ignore a lot of bad behaviour, unless it was dangerous, and commend good behaviour as a positive reinforcement. That's not what's really happening because Lance has been in time out quite a bit.

Gaby reasoned that Lance, who had a diagnosis of Asperger’s, might be better off in the more segregated environment of an autism-specific school, where she hoped the staff would be better trained. She moved her son there the following year.

In particular, autism experts within the education system may exhibit rigidity and an excessive adherence to routines. Melissa described how, on the second day of her son’s enrolment in a regular classroom, an autism outreach teacher visited. She drew a circle in chalk on the carpet and told Callum that he was to remain within its bounds. When Melissa later questioned the logic of this strategy, the expert replied that ‘some autistic children respond better if they have a specific circle to sit in’. Callum was unconvinced by this circular logic and refused to sit there. Natalie told me that an autism outreach teacher had removed the sensory equipment provided by an Occupational Therapist because she didn’t want Evan ‘to look different’.

Whether demanding or refusing autistic difference, the behaviour of teachers, especially those with special autism expertise, is sometimes characterised by inflexibility. ‘They are so set in their ways’, remarked one concerned mother. ‘The autism outreach teacher and his teacher are

just too black and white to understand anything', contributed another. Where the classification of autism becomes detached from specific individuals and is replaced by *educator reactions limited by stereotypes prompting inflexible behaviour* a diagnosis of AID is usually appropriate.

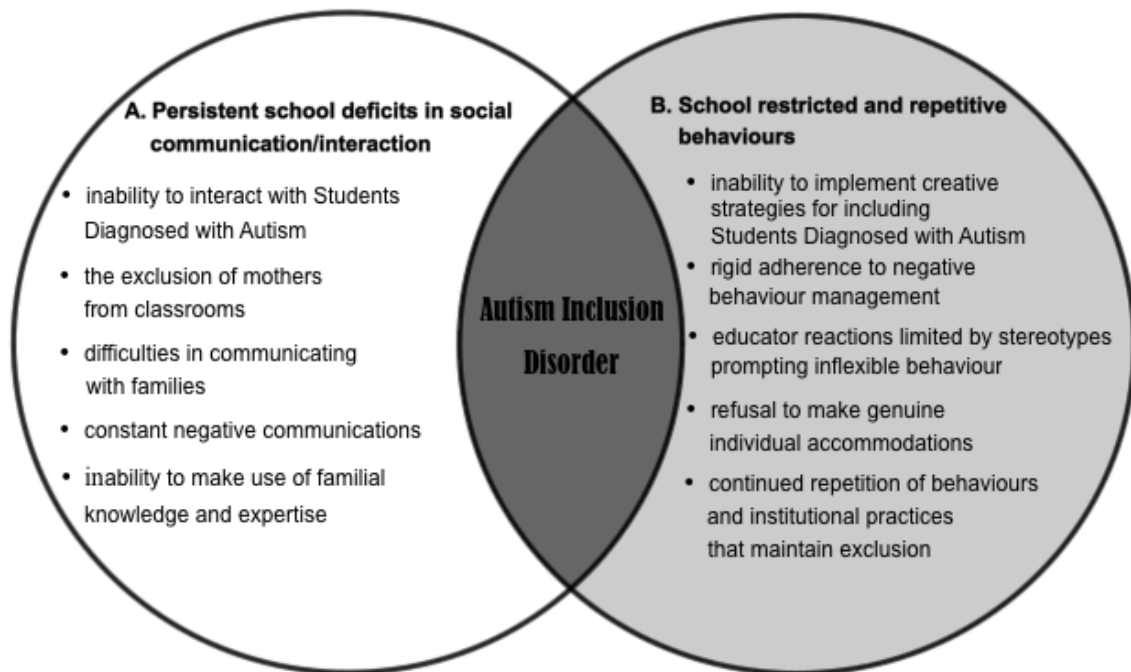
School behaviour must be repetitive as well as restrictive to qualify for this diagnosis. This tendency towards the repetitive is most often observed in the *refusal to make genuine individualised accommodations* to support SDWA through the rigid insistence that 'this is how we do it'. The school deficits endured by Todd are instructive here. Positive behaviour management strategies suggested by his mother, including a visual timetable on his desk and rewards of computer time for task completion, were rejected on the grounds they would make Todd 'look different'. Teachers also refused any curriculum differentiation, telling Sally: 'Well, he's here in a mainstream school, so he's doing the work that everyone else is doing'. This repetitive insistence on school sameness eventually led to Todd enrolling in a special school.

Difficulty with change and with transitioning towards inclusion may lead to the *continued repetition of the behaviours and practices that maintain exclusion* or, in milder forms, integration. This is clearly seen in the two cases of mothers who transitioned their children from autism-specific special schools to either less segregated or more inclusive settings against the advice of special educators. Both of these women firmly resisted practices designed to maintain exclusion, insisting on their child's right to transition out of special school placements.

Lena was discouraged from moving Guy, who is categorised as having moderate ID, from the autism-specific school he attended. She told me that Guy was being academically underestimated and developing challenging behaviours, which she attributed to the modelling of his peers. Her efforts to find a less segregated setting were, she believed, being deliberately sabotaged by Guy's teachers who advised education professionals from other schools that he was 'not ready' for a less restrictive placement. Eventually, Lena contacted the government sector and sought enrolment for her son in the less segregated setting of a support class. Having learned from previous experience, she refused permission for the government school staff to either observe Guy at the special school or talk to their staff.

Angela was surprised when the autism-specific school Jarrod attended decided he was not suitable for transition to a support class. Many of his peers were moved 'up' after their first year and Angela felt that her 'high functioning' son was not being intellectually nurtured at his special school. The special school, however, insisted that Jarrod, due to high levels of anxiety, was not

ready to move to a less segregated placement. In response to these efforts to maintain exclusion, Angela withdrew her son and enrolled him in a mainstream school in the government sector.



*Figure 8.2: Defining features of Autism Inclusion Disorder or AID.*

Unfortunately AID, based on observation of the co-presence of persistent school deficits in social communication/interaction and school restricted and repetitive behaviour, can be found in both segregated and mainstream classes in NSW. Care must be taken with detailed observations of all schools as some may adopt a rhetoric of inclusivity while persevering with or even adopting novel practices that promote ‘micro-exclusion’ (Cologon 2013; Wendelborg and Tossebro 2008). Others may resist parental efforts to seek less segregated or more inclusive settings. AID is perhaps most apparent when SDWA change schools, usually in the direction of more segregated options. Considered more broadly, AID is a subset of School Disability Inclusion Disorder.

On a more positive note, if we look at the larger data set of 22 students we find that that 7 of the 11 who enrolled initially in regular classes in mainstream schools remained there. None of these students had a concurrent diagnosis of ID. While one of their mothers indicated ongoing difficulties with the school and another expressed growing concerns during the third and final

interview, the other five families were very satisfied with their child's experience of and inclusion in primary school. Most were being resourced by available mechanisms in both the government and the Catholic sectors. So while AID may have a worrying prevalence, this is, to some extent, counterbalanced by trends pointing to the efficacy of educator practices based on a genuine commitment towards inclusive education.

### **Changing Students or Changing Schools?**

As inclusive education commentators have pointed out (e.g. Cologon 2013; Graham and Spandagou 2011), the difficulties that students experience in school are usually interpreted as a failure of the child to adjust. The preceding outline of the defining features of AID was, like many parodies, designed to draw attention to a very serious political issue.

That issue is the extent to which it is schools rather than students that need to change in order to achieve inclusive education. This focus on school change or, more broadly, on the social context within which the student with a disability is embedded, is consistent with social models of disability that emphasise the ways in which environments (and, by extension, politics) construct disabilities through disabling practices. These disabling practices generally rest on modes of thought that see disability as located within the body/brain of an individual who requires therapies and other interventions, possibly including medications, to assist them in transforming towards 'normality' or, at least, docility.

Parents often share the notion that their children must change to fit the education system. Thus Jana expressed the view that 'it really depends on the child whether they can handle to be included in school or not'. Camila offered a refreshing take on this common perspective:

Oh my God, I'm hoping he's going to be a regular kid like all the other kids. He's going to be able to go to assembly and sit there and listen to their crap for 20 minutes, because it is bloody boring.

Where mothers feel that their child cannot fit in, they often choose to send them to a segregated setting where they trust they will be safe and their perceived deficits may be remediated through the pedagogical techniques of special education (Cole 2005; Runswick-Cole 2008).

Three of the eight mothers whose school change narratives have been analysed were advised to medicate their children in order to make them fit better into mainstream school. The ABA therapy centre Melissa's son attended advised her to try him on Ritalin prior to school entry



‘to see if it improved his attention’. His paediatrician agreed but Callum developed motor tics and became verbally abusive and so the medication was stopped. Teachers suggested to Sally that her son might benefit from medication for Attention Deficit Hyperactivity Disorder and, again, a paediatrician agreed with the school’s suggestion. This child, too, had a negative reaction to the medication.

Angela’s son was prescribed Ritalin and Risperdal following teacher encouragement. While she judged both as effective for Jarrod, she also gave an astute account of how it is classrooms that create the need for medicated students:

Well, I think it’s really interesting that they start in school, and I think that’s because they go into such a structured setting, where there’s so much language – not a lot of room for them to move around and do the things that they need to do to settle and so forth. So you know, I’ve put him into an environment in which he just doesn’t really function very well, and we’re all expecting him to function. Now, if I could keep him in those environments where he was able to be himself, he probably wouldn’t need all the medication.

Angela’s narrative illustrates the difficulty SDWA can have in some school contexts and the conflicted maternal feelings evoked by the demand that ways be found to make these students conform to classroom demands and expectations. For her, the locus of difficulty is not with Jarrod; it is to be found in his environment. Her views express informally what many sociologists of education have long pointed out – ability and disability are not traits possessed by individuals; they are ‘part of the social system of the school and the society’ (Mehan, Hertweck and Meihls 1986, p.164).

Interviews with mothers often revealed distrust of and anger towards the schools their children attended. Indeed, sometimes the perspective of schools and parents about SDWA are incommensurable. Jana, for instance, spoke disbelievingly about an IEP meeting at the autism-specific support class Tony went to. Faced with a string of negative observations about her son, she could only reply ‘that’s not my child you’re talking about’.

These maternal school change narratives suggest that to develop a genuinely inclusive education system more attention should be paid to changing schools rather than changing children to be compliant within traditional classrooms. Given the additional difficulties SDWA often have in dealing with change and the particular distress caused by educational transitions to

unfamiliar settings for this cohort (Stoner et al. 2007), there is an urgent need to encourage educators and school bureaucrats to find ways of responding flexibly and creatively to the needs of all learners. As Cologon (2013) has recently argued in the Australian context, conditional assimilation is not inclusion; adapting schools to ensure the valued participation of all learners is.

Many of the practices that would promote inclusive education have been written about elsewhere (e.g. Booth and Ainscow 2002), and a number of these texts explicitly address inclusive education for SDWA (e.g. Kluth 2003). If we reverse the descriptors of AID we find two central components of autism inclusion: *persistent school efforts in social communication/interaction* (including teachers taking responsibility for SDWA; the welcoming of parents into classrooms; frequent positive communication between home and school; the recognition and valuing of familial expertise) and *school expanded and flexible behaviours* (including the implementation of creative strategies; positive behaviour support; a focus on the capacities of individual students; a willingness to make accommodations; an acceptance of the value of inclusive education for all students). This is, in many ways, a concise summary of many of the suggestions previously made by advocates for inclusive education. The more novel contribution of this research is the documentation of the extent to which mothers are aware of exclusionary behaviours and practices and their active role in moving their children to different schools in response to these. As previously noted, six of the eight mothers moved their children to more segregated classroom settings. They felt they had run out of other options. This fact alone is eloquent testament to the ongoing necessity for improvements in the delivery of inclusive education in NSW.

### **Conclusion: Autism Inclusion Disorder and Maternal Perspectives**

This research has suggested that mothers often initiate school changes as part of a wider pattern of maternal responsibility for the wellbeing of SDWA. These decisions are usually made in response to student distress and, sometimes, school refusal. A concern to find schools that will foster learning in an environment where their children are contented lies at the heart of many school change decisions. The eight cases of school change analysed here provide a stark picture of the extent to which our classrooms and schools, mainstream and segregated, are either unable to adapt to SDWA or resist inclusive education. Rather than searching for the causes of these difficulties in the behaviour of students, I have argued that we will gain a valuable perspective if

we look at the pattern of deficits found in classrooms and schools, as described by concerned mothers. This pattern has been referred to as Autism Inclusion Disorder.

International research frequently finds that increasing numbers of students with disabilities are educated in regular classrooms (e.g. Wendelborg and Tøssebro 2008). This is not the case for the 22 families of SDWA in NSW, Australia, who participated in this research. Over the first three years of primary school there was a marked shift towards segregated schooling in either support classes or special schools for these students. This early primary school drift towards segregation for SDWA should be of great concern to educators and policy-makers.

The stories these women told were about the small details of everyday school and classroom practice and the ways in which those practices either worked to include or exclude their child. Most of these mothers were indifferent to the abstract concept of inclusive education. In other words, while some schools remain unable or unwilling to offer inclusive education, mothers, in the best interests of their children, will continue to make use of the segregated options that are available. Despite the policy shift towards inclusive education in NSW, the reality is that for many SDWA and their families, inclusion continues to be fragile, contingent and disappointing. The inability to include SDWA is not simply a reflection of student characteristics. Rather, what we find mirrored here are ongoing features of institutional practices involving either efforts to maintain segregation or unreflexive practices of informal exclusion. In these circumstances we should be focusing on how schools, not students, need to change.

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## Chapter 9

### Discussion

Still, it would be progress if we could acknowledge that there really is no such thing as ‘the normal child’; instead there are *children*, with varying capabilities and varying impediments, all of whom need individualized attention as their capabilities are developed (Nussbaum, 2006, p. 210).

This dissertation is based on analysis of the experiences of 22 mothers whose children diagnosed with autism were transitioning to primary school in Sydney, Australia. The tensions between the aims of inclusive education and the continued provision of segregated classrooms and schools in NSW forms a backdrop for exploring processes of ‘choice’ and ‘placement’ (informed by expert and lay knowledge), stigma and exclusion, and school change. Central to the research is the question of how this group of mothers negotiated school entry, including the forms of pragmatic and affective maternal work required by this important transition. Listening to and respecting these women’s experiences provides a valuable perspective on the lives of both the cared for (children diagnosed with autism) and those who care for them (mothers).

The mothers all volunteered to participate, with the first of three annual interviews taking place in the year before their children started school for the first time. All of the children being discussed had autism spectrum diagnoses before they entered the education system. In other words, their impairments and developmental differences were sufficient to warrant a formal diagnosis between the ages of 3 and 5. Accessing mothers prior to their child’s school entry meant that their participation was not motivated by negative encounters; rather, their stories newly unfolded along the three-year timeline of the research project.

The narratives of these 22 mothers cannot represent the full range of experiences of the thousands of families with children diagnosed with autism who currently attend schools in NSW. Quantitative data as well as additional qualitative studies are needed to track and further illuminate the experiences of these students and their families. Nevertheless the purposive sampling used for this study allowed access to families whose children were placed on the autism spectrum and who were attending the full variety of education settings in NSW (regular classes, support classes and special schools) in all three sectors of the education market (government, Catholic and Independent).

The longitudinal nature of the research, with multiple interviews occurring over three years, has allowed a sense of changes over time and assisted in developing a more detailed and intimate picture of the everyday lives of these mothers as they engaged with the formal schooling system. The maternal narratives analysed across these publications provide a rich source of material for investigating many of the mechanisms in the education system through which children considered to be developing atypically continue to be classified and sorted. They also reveal a great deal about the extent of women's labour, and the socio-political frameworks within which that work is an unquestioned expectation of those who mother children experiencing disability.

My approach throughout has been to contextualise maternal narratives within a larger scholarship, locating the personal accounts of these 22 women as part of broader (often sociological) understandings of disability and schooling. Their experiences are nearly always echoed, and sometimes amplified, by the writings of other scholars. In this sense, the research presented here frequently provides confirmation of many of the findings of a much wider literature. In turn, that consistency with the available literature confirms the relevance of this research.

### **School 'Choice' and Autism: Entering the School System**

In Australia, education is the responsibility of individual states and territories. Consequently each jurisdiction has its own Education Act and there are varying agendas and practices regarding the education of students experiencing disability (Forlin, 2006). Despite these regional variations, there is an overarching federal commitment to inclusive education, expressed in a range of documents and policies (Cologon, 2013). In particular the Disability Standards for Education 2005, formulated under the *Disability Discrimination Act 1992*, seek to ensure that students experiencing disability can access and participate in education on the same basis as other students (DEEWR, 2012).

Definitions of inclusive education vary widely, and are the subject of strenuous debate. In this research I have viewed the placement of a child diagnosed with autism in a regular classroom as a potential indicator of inclusion. However, I have also recognised that forms of micro-exclusion can occur within regular classrooms (Cologon, 2013). Being welcome as a valued member of a class is the foundation of genuine inclusion. Lindsay and colleagues (2014, p.102) provide a succinct formulation of this view, arguing that inclusion occurs when each child is an

‘equally valued member of the school culture involving presence, participation, acceptance and achievement’.

This research is set in Sydney, the capital of Australia’s most populous state, NSW. NSW is an interesting location to consider some of the complications of achieving inclusive education. Although approximately 75% of students experiencing disability are enrolled in the government school sector (NSW Government, 2010), parents may also consider schools in the Independent and Catholic sectors. Every child experiencing disability has the right to attend their local government school, but both the government and Independent sectors have maintained the option of segregated schooling in the form of special schools and support classes (Powazuk, 2013).

Autism was introduced as a funding category in the NSW government school sector in 2004. In the ten years since then there have been significant rises in the number of children enrolled in primary support classes under the autism category (Graham & Sweller, 2011). Furthermore, NSW is home to the largest autism specific education service provider in the world. Autism Spectrum Australia (Aspect) operates eight Independent schools in NSW, catering to nearly 1000 students. Many of these students attend support (‘satellite’) classes housed within government and Catholic schools but staffed by Aspect teachers and paraprofessionals. Indeed, in 2011 Aspect and the NSW Department of Education signed a Memorandum of Understanding to provide a formal framework for the provision of these autism-specific classrooms and other services within the government sector (NSW Government, Education & Communities, 2011).

So although there is a policy commitment to inclusive schooling, the provision of segregated placements for students diagnosed with autism appears to be expanding in NSW. This continued provision of segregated placements, known as a range or continuum of educational services, is supported by the Autism Advisory Board (2010), a national peak body of experts. It is also supported by numerous educators and parents.

Clearly, then, there are many tensions operating between the goal of inclusive education and the continued, and expanding, provision of segregated school placements for students diagnosed with autism. Parents are told that it is their ‘choice’ as to where they want their child to go to school. But they are also often informed that their child will be better off in a special school or support class where their needs may be better met through smaller classes, more intensive resources and the potentially remediating effects of special education expertise. Parents may also have been informed that their child will probably be transitioned to a less segregated or more inclusive classroom placement over time (Chapters 3 & 6).

To summarise, there are many moving parts between the intuitive social justice of the idea of inclusive education, the provision of education services and the actual experiences of families. In the following I outline and discuss the major findings of this research on maternal experiences of school choice and school change for students diagnosed with autism in NSW.

## **Overview**

This Discussion proceeds by addressing some of the major issues raised by this dissertation, and their relationship to the original research questions. The first three sections are focused on the findings and implications of this research in relation to students diagnosed with autism and the current education landscape in NSW. The remaining sections are more explicitly directed towards experiences of mothering in the context of transition to primary school

In the first section, ‘Segregation, stigmatisation and sorting’, I argue that students diagnosed with autism continue to be subject to processes of sorting, which direct some towards segregated placements and others towards regular classes in mainstream schools. In particular, students with a concurrent diagnosis of autism and intellectual disability are still thought of as ‘belonging’ in special schools or support classes, and mothers continue to find these environments attractive, partly because they have internalised the logic of the sorting system but also due to the frequent inadequacies of mainstream education for students with high support needs. I also argue that autism stigmatisation has not decreased. In fact, mothers frequently encounter stigmatisation when they attempt to enrol their children in mainstream schools.

In the second section, ‘School change and autism’, I revisit maternal narratives of school change, and consider some of the implications of these narratives for inclusive classroom practice in both mainstream and segregated settings. In the third section, ‘Inclusive education for students diagnosed with autism in NSW?’, I take a look at what the ‘drift towards segregation’ documented for this sample tells us more broadly about some of the current autism education landscape.

This dissertation has highlighted the extensive expectations placed on mothers of students diagnosed with autism to navigate complex systems of service provision, and to act as mediators and advocates for their children. I have also considered the impact of these demands, as well as the effect of stigmatising attitudes and exclusionary practices, in forging maternal identity. These pragmatic and affective tasks have been linked through Goffman’s (1963) concept of moral careers.

In this Discussion these moral careers are delineated in three sections. The first ‘Encountering exclusion’ briefly reprises the impact of stigmatisation and exclusion at the point of primary school entry on mothers. The second section, ‘Negotiating knowledge’, brings professional guidance and rumour together as twin frames of knowledge, which women negotiate as part of their efforts to understand the system of education service provision and to enact projects of ‘good’ mothering within this complex landscape. Finally, in ‘The moral imperative to care’, I summarise the extent of women’s care commitments at the transition to primary school and the continued force of gender ideologies that make them primarily responsible for their children. Accepting this responsibility, and learning to operate within a series of institutional frameworks and professional practices that channel their children into differently imagined futures depending on their perceived abilities, is an integral part of their developing moral careers as ‘autism Mums’.

Following these sections on the major themes of the dissertation, I consider some of the limitations of this research and other methods that might usefully contribute to understanding the experiences of students diagnosed with autism and their families. In doing so, I canvas some possibilities for future research directions. A short section, ‘Drawing connections’, then contextualises the research in terms of my own family’s unfolding careers. The Discussion comes to a close with a summary of the arguments in the dissertation and some concluding remarks.

### **Segregation, Stigmatisation and Sorting**

One of the questions guiding this research was: *What factors are relevant for mothers in determining school choice and school placement?* In the previous section I noted some of the structural properties of the education landscape in NSW, including the simultaneous presence of segregated and mainstream schooling options and a large independently operated system of autism-specific provision, which has agreements with the government and Catholic sectors. I suggested that these options run against the grain of Australian legislative commitments to inclusive education. Mothers, who undertake much of the work of school choice, and also mediate processes of school placement, are thus confronted with a complex field of education provision for students diagnosed with autism.

The first publication, *Mind the gap*, approached the question of relevant factors by looking at the reasons why nine of 22 participating women initially enrolled their children in segregated settings. Little had changed, I argued, since Jenkinson’s 1998 study identifying the

attractions of special education expertise for parents of children experiencing disability. Parents are often torn between wanting to send their child diagnosed with autism to a regular class in a mainstream school and worrying that they will not be properly helped or looked after in that environment. The promise of specialist educators in segregated settings who are trained to remediate the impairments associated with autism remains a powerful attraction.

I noted that the substantial gap between the promises of inclusive education and the reality of limited resources and accommodations in regular classrooms fuels the continued enrolment of students in either support classes or special schools in NSW. Further, ideologies that equate good mothering with making a ‘sensible’ choice to segregate are pivotal in both directing women towards this outcome and in providing a retrospective explanation for these decisions. The majority of the children being placed in a support class or special school in this sample had concurrent diagnoses of autism and ID. In general, mothers accepted the idea that their child belonged, and would be better looked after and equipped with basic living skills, in segregated classrooms.

In the second publication, *It's an absolute nightmare*, I focused on the research subquestion: *Do mothers feel they and their child are subject to forms of social stigma during the transition to primary school?* The question was prompted by a trend in the literature to argue that the stigmatisation of individuals experiencing disability and their families has substantially weakened in recent decades. This article addressed the issue of the extent to which autism stigma is experienced in primary school transitions through an analysis of maternal narratives of exclusion or attempted exclusion, provided by ten of the 22 mothers. These narratives were mainly about mainstream schools.

Because segregated settings are explicitly established to ‘deal with’ students with impairments, mothers rarely encounter overt interpersonal discrimination in these closed environments. In the mainstream education system in NSW, however, systemic intolerance for students diagnosed with autism persists. School gatekeepers (predominantly those employed in school leadership positions such as Principals, as well as administrative staff) mobilised stigmatising attitudes, resting on negative stereotypes of students with autism, in their attempts to exclude. The most common strategy of exclusion was an appeal to inadequate resources followed by deflection (sending mothers to other schools). However in the most extreme case a local government school attempted to deny enrolment to a student with an autism diagnosis, partly on

the explicitly articulated basis that he was likely to bring down their scores in standardised national testing.

These maternal accounts led me to argue that the link between stigma and disability is not, as some commentators have argued, decreasing. Certainly, for many of the families in this sample, autism continued to be reproduced as a disabling category in everyday interactions with school gatekeepers. This occurred with sufficient frequency to suggest structural discrimination in that these accumulated practices work to the potential disadvantage of all students diagnosed with autism.

Another research question informing this project was: *Has the broadly stated Government commitment to inclusive education made a genuine impact on schooling for the students in this sample?* Two of the publications, *Mind the gap* and *Professional guidance*, provide partial answers to this question.

If we look at what happens to students with a concurrent diagnosis of autism and ID, the answer is a resounding ‘no’. All seven children in the sample who had a diagnosis of moderate or severe ID were initially segregated, and then remained in segregated classrooms throughout the period of this research. One of these seven mothers moved her son from an autism-specific school to a government support class. Once there, however, her son remained within a system of segregated provision. In other words, on the basis of this sample, inclusive education is still only considered feasible for those judged more intellectually able. Or, to put it another way, groups of children are still being excluded from regular classrooms on the basis of their measured cognitive incapacities.

Turning our attention to those students (eight) in the sample labelled ‘high functioning autism’ (HFA) or Asperger’s syndrome (one), we find that the majority were directed towards mainstream provision. However two of these nine children were initially enrolled in segregated settings. Some of the mothers of these students reported that there was conflict between the advice offered by early intervention professionals, who advocated for mainstream provision, and school gatekeepers, who attempted to deflect or exclude these same students. Nevertheless, the remaining seven students in this subset were, at the start of 2010, enrolled in regular classes in mainstream schools. Six of these students remained there for the duration of this research. One of these nine children moved from an autism-specific school to a regular class (against the advice of educators at the special school); one moved from a regular class to a support class and then a

special school and another, the student diagnosed with Asperger's, moved from a multicategorical support class to an autism-specific school.

Taken as a whole, we can see that there is a strong link between educational placement and students' diagnostic categorisations. Those considered least capable are directed to segregated classrooms. Those considered most capable are generally enrolled in regular classes in mainstream schools, with additional support. Challenging behaviours or assessments of greater autism severity alongside 'normal' cognitive capacity, however, can result in children labelled HFA being channelled into segregated settings.

So far the picture presented in this sample of the sorting of children diagnosed with autism into education streams is straightforward – students deemed high-functioning usually enter the mainstream while those with ID are placed in segregated provision. As discussed in *Professional guidance*, it is the students labelled 'borderline' who trouble these neat divisions. All of the mothers of so-called borderline children received conflicting professional guidance and were, consequently, caught in the divide between mainstream and segregated education possibilities.

The experts who exert the most leverage in these decisions are educational psychologists. Their assessments of the cognitive potential of students, in the form of psychometric evaluations, have the greatest influence on decisions about 'appropriate' placement. Children's diagnostic placement within the arc of the autism spectrum thus has an immediate impact on the extent to which mothers feel able to exercise choice. Those students diagnosed with autism and ID were placed by professionals. Mothers of these students sometimes decided which segregated setting to enrol their child in but, in this sample, none felt that a mainstream school was a genuine option. Those labelled 'borderline' tended to trouble the system of funnelling into 'appropriate' settings, with professionals sometimes disagreeing over what kind of classroom would be best for these students. Mothers of children considered 'high functioning' were most likely to choose mainstream schools. Indeed, they sometimes felt that they received very little professional guidance and complained about the lack of segregated options that were suitable for their child.

In sum, the experiences of mothers who participated in this research strongly suggests that in the NSW education system a) students diagnosed with autism continue to be sorted by experts according to their perceived capacities and (in)abilities; b) families are often subject to overt forms of stigmatisation and attempts at educational exclusion at the point of attempted enrolment



in mainstream schools; c) segregated settings are still presented as the only sensible choice for students with an additional diagnosis of ID.

### **School Change and Autism: Moving Around the System**

In *Trading places*, the final article in this dissertation, I analysed maternal narratives of school change. This publication directly addresses the research sub-question *When children are moved from one school setting to another, what factors have led to this change?* Nine of the 22 students in this sample changed schools in their first two years of formal education. One move was due to geographic mobility. The remaining eight of these changes were due to difficulties students were experiencing in their first school, causing considerable distress to both the student and their family. While many mothers reported a sense of acquiescing to professional judgments during the process of initial school enrolment, this picture changed dramatically when mothers became dissatisfied, over time, with education provision in a particular setting. In this situation mothers often became staunch advocates, offering scathing critiques of schools and classroom practices. These mothers were often both disappointed and angry. In their efforts to help their children, some proved adept at marshalling their own experts to challenge the opinions of professionals situated either in their child's school or within a particular system of education service provision.

The most common complaints of mothers were that: i) teachers did not take responsibility for the students diagnosed with autism, tending to rely on paraprofessional support; ii) mothers felt unwelcome in their children's classrooms; (iii) there was limited or persistently negative communication between home and school, focusing on child deficits; iv) school staff undervalued familial knowledge and expertise. Mothers also reported the use of negative or punitive behaviour management and inflexible attitudes to classroom practices and routines, including a refusal to make suitable accommodations for students diagnosed with autism.

Most, but not all, of these maternal criticisms were directed at the provision of education in regular classes in mainstream schools. Perhaps surprisingly, however, mothers reported some of these problems in segregated settings, with the most intense complaints of feeling 'shut out' and unwelcome emerging in the context of autism-specific schools and classrooms in the Independent sector.

A fundamental tenet of inclusive service provision across a range of sectors is 'the fact that *equitable* is different from *the same*' (DEEWR, 2012, p. 14). Mothers pointed to the

excluding outcomes when school bureaucrats and educators maintained the outdated view that all children in a classroom have to be doing the same work and receiving the same level of supports.

Two of the eight students who changed schools enrolled in more inclusive or less segregated settings: one moved from an autism-specific special school to a regular class in a mainstream school and one moved from an autism-specific special school to a multicategorical support class. Six of these students moved to more segregated provision. Two went from support classes to special schools. The remaining four students were shifted from regular classes in mainstream schools (in the Independent, Catholic and government sectors) to either support classes (one) or special schools (three).

Listening to maternal narratives of school change allows us to grasp some of the features of institutional practice that create the conditions for micro-exclusion and encourage the drift towards segregated provision for students diagnosed with autism in NSW. If inclusive education is to gain a firmer foothold, schools and classrooms need to embrace both attitudinal and pedagogical change to better meet the needs of diverse students. These processes are interlinked. Building the capacity of the education system and the capability of schools to effectively support all diverse learners, including children diagnosed with autism, is one step. Shifting entrenched social attitudes, in particular the stigma attached to autism and to ID, is another. Until these interlinked processes are more fully achieved, parents, as well as many of the professionals effectively making placement decisions, will continue to opt for specialist schools because of the shortcomings of the mainstream system (PricewaterhouseCoopers, 2011). When doing so, the problems that students may experience in segregated provision tend to be downplayed or overlooked.

### **Inclusive Education for Students Diagnosed with Autism in NSW?**

The longitudinal design of this research provided a picture of considerable flux between school settings for this sample of 22 students. These changes were usually in the direction of more segregated provision. This suggests that the legislative and policy commitments to inclusive education in Australia are having a limited effect on outcomes for a proportion of students diagnosed with autism in NSW.

The picture presented here of a drift towards segregation finds confirmation in other research. Analysing recent trends in education placement in NSW government schools, Graham and Sweller (2011) have argued that two processes are at work – a rapid growth in the number of

students with a diagnosis of disability eligible for support in regular classes *and* an increase in the enrolment of students with particular diagnostic categories (including autism) in segregated settings.

*Trading places* pointed to the difficulties some students diagnosed with autism were experiencing in regular classrooms in mainstream schools. These difficulties were a major cause of school change. Nevertheless, seven of the 22 students in this sample remained in regular classes in mainstream schools, and their mothers reported largely positive experiences in these settings.

If we look more closely at this subset of seven students (approximately one third of the sample), we find that six of them were enrolled in government schools and one attended a Catholic school. In terms of student characteristics, all of these children were located either on the margins of the autism spectrum (with three having a diagnosis of PDDnos, indicating fewer observed autistic traits), or were considered very high functioning. Indeed, a number of these mothers did not disclose their child's diagnosis to other mothers at their school. This simply would not have been an option for many of the women interviewed.

As discussed throughout this dissertation, the criteria for autism diagnosis have, over the years, broadened. This has meant that the number of children caught in the net of autism diagnosis has also radically expanded. Based on the experiences of families participating in this research, it seems clear that the NSW education system, especially government schools, are successfully supporting some students with a label of HFA or PDDnos. These are precisely the same children who are, due to the increasing identification of autism, likely to have been caught up in the sweep of this larger diagnostic net. Conversely, the mainstream education system has continued difficulty in adapting to the needs of students labelled with both autism and ID or challenging behaviour. Inclusion thus remains contingent on individual student characteristics.

Professionals involved with the sorting of students would, in all likelihood, perceive this sample as indicating the success of their efforts to place children diagnosed with autism in appropriate settings. Those placed in segregated settings remained there, and many of those who were advised to try regular classes in mainstream schools also stayed put. Some movement across these settings (largely in the direction of more segregated provision) is to be expected. Indeed, the general picture provided by this research could be taken as confirmation of the continuing need for a continuum of services and placement options.

However, if we look at this same data from the vantage point of a commitment to inclusive education, our perspective alters. Instead of seeing appropriate placement we notice that children continue to be sorted and streamed, and that the notion of the impaired and defective student sits at the heart of these processes. We also observe the increasing number of segregated placements, and the ways in which the notion that specialist education is required for particular disability labels creates and justifies this expanding provision.

Judging from this sample, it seems that most students diagnosed with autism only remain in regular classrooms when they follow existing norms for classroom conduct and meet similar expectations of academic performance to their peers. The notion that inclusion is only suitable or practical for some students is, at best, integration. Stereotyping, stigmatisation and sorting, I have argued, sustain systemic practices of education exclusion in NSW. A diagnosis of autism continues to have many implications for school placement and the consequent paths of student careers. Research that extended the geographic coverage of these issues to the other Australian states and territories would further contribute to our knowledge of some of the current challenges involved in implementing inclusive education.

### ***I Was New in the Game Back Then: Mothers, moral careers and primary school transition***

The major question that guided this dissertation was: *What kinds of care, both pragmatic and affective, are mothers engaged in as they negotiate the transition to primary school of children diagnosed with autism?*

Mothers of children diagnosed with autism come to the experience of primary school transition having already encountered a number of fundamental shifts in their sense of what mothering might entail. There is a profound ‘distance between the experience of being a mother and the experience of being the mother of a disabled child’ (Ryan & Runswick-Cole, 2008, p. 200). Women repeatedly underlined this difference to me in conversation, struggling with both the practical enormity of their responsibilities and with the effort to find ways of incorporating disability within an altered familial imaginary (Rapp & Ginsburg, 2011).

Medical models of autism present families with a devastating diagnosis, and an almost entirely negative prognosis. Within the medical model, autism is perceived as a lifelong neurodevelopmental disorder characterised by a series of impairments in social relating and communication, as well as repetitive behaviours. Cognitive impairments are commonly paired with autism. Families are told that their child will never fully ‘recover’ and that their chances of

ever living a fully independent life are slim. Autism diagnosis is, therefore, presented as a tragedy, both for the child diagnosed and for their immediate family (Lilley, 2011a).

Grappling with the affective aftershock of diagnosis, mothers then find themselves immersed in the controversial field of autism interventions. Therapies are diverse; promises and pitfalls numerous. The financial costs of intensive therapy, widely reported to achieve the best results, are staggering. The bureaucratic demands of navigating early childhood provision for children diagnosed with autism are strenuous. Various government packages need to be accessed, organisations contacted, information sifted through, and waiting list applications completed. And all of this must be done quickly, mothers are told, if their child is to have any genuine hope of significant improvements. Early childhood is represented as a window of opportunity for undoing impairments through intensive therapy. As the months pass, parents fear that this window of potential transformation towards normalcy comes ever closer to being closed (Lilley, 2011b).

Mothers may become quickly skilled in these tasks, and often take pride in their capacity to sift through information and to access services and therapies. As one mother said to me, reflecting back on the time when she began searching for early intervention services in the telephone book, 'I was new in the game back then'. This growing competence in managing the various demands of helping, and being seen to help, a child diagnosed with autism is largely achieved in the early intervention sector. Professionals in this 'helping' sector are generally very adept at stressing the capacities of children experiencing disability and at providing a supportive environment for families. Women may develop close relationships with therapists who offer a hopeful frame in relation to the possible trajectories of their children.

Goffman's conception of 'moral careers' is especially helpful in understanding the unfolding pattern of these mothers' lives. Mothers of children diagnosed with autism tend to have similar learning experiences regarding their situation and, often, similar changes in conception of self. They share 'a similar sequence of personal adjustments' (Goffman, 1963, p.32). The first of these adjustments is diagnosis, a period in which mothers are usually swept up in grief over developmental difference and the disabling predictions of the medical model (Lilley, 2011a); the second is early intervention, during which mothers are expected to become deeply committed to facilitating therapeutic claims of improvement (Lilley, 2011b); the third is primary school transition. It is this third area that is the focus of this dissertation.

## **Encountering Exclusion**

Following the supportive experience of early intervention, including individualised attention directed towards children, an emphasis on capacities and a hopeful orientation towards the remediation of impairments through intensive therapy, mothers then encounter a much more mixed set of attitudes during their child's transition to primary school. As documented in *It's an absolute nightmare*, they may face exclusionary attitudes and stigmatising responses, especially from school gatekeepers in mainstream education settings. Maternal narratives of school exclusion suggest that mothers were often actively pushed around by school gatekeepers who adopted a range of strategies to keep out children diagnosed with autism. Maternal tactics in response to these stigmatising strategies were, in many instances, resilient and resistant.

It is not only children who are stigmatised by school gatekeepers. Mothers, too, felt devalued and discriminated against in the course of excluding encounters. I explored this felt stigma in *Crying in the park*. In this publication I built on Goffman's (1963) notion of courtesy stigma, whereby someone who associates with a stigmatised person is thereby stigmatised, to understand something of these dynamics. I offered the alternative term 'attachment' stigma as one way of referencing the twin impact of a) the very close intersubjective relationship between mothers and children experiencing disability, built on prolonged dependency, and b) the circulation of gendered ideologies, which render mothers responsible for their children. In the case of mothers of children diagnosed with autism this maternal responsibility is still wrapped up in the legacy of a history of maternal culpability, most floridly expressed in the psychogenic paradigms of the 1950s and '60s, which posited cold mothering as a cause of autism (Bettelheim, 1967; Kanner, 1943).

## **Negotiating Knowledge: Mediation, Advocacy and Maternal Agency**

For all of the mothers in this sample the transition to primary school was characterised by active engagements with professional guidance, as well as grapevine knowledge, largely gleaned from other mothers, about the pros and cons of various school settings. One of the research subquestions was: *How involved are families of children diagnosed with autism in the transition to school process?* Thinking about this issue involved grappling with the intersections between maternal agency and various forms of knowledge, including expert and lay approaches to autism and education. The ways in which these knowledge frames shaped maternal views and impacted

on school decisions was addressed in two publications, *Professional guidance* and *Rumour has it*. These publications are best read together, as offering different perspectives on how it is that children diagnosed with autism end up in particular schools or classrooms in contemporary NSW.

Most mothers (17 of the 22) reported conflict in the professional guidance they received. Thirteen remarked on strong disagreements in relation to school enrolment. This provides an important counterbalance to my previous depiction of smoothly operating set forms of streaming for students diagnosed with autism. It points, in part, to the considerable work involved in achieving those streaming outcomes. But it also directs analytic attention to the adjustments and fractures in the education system, as both professionals and parents debate where children with widely differing abilities and characteristics, all caught in the net of autism diagnosis, should go to primary school. As we have seen, these disagreements and uncertainties were most strongly apparent in cases where children were labelled ‘borderline’.

Mothers were profoundly influenced by professional advice about the best placement options for their child. As noted throughout this dissertation, the term ‘professional’ covers a wide variety of experts operating within the autism matrix, including those more associated with early childhood (therapists, paediatricians, preschool teachers) and those who are part of the education sector (educational psychologists, education disability advisors, administrators, Principals and primary school teachers). Sometimes these professionals were in direct conflict. In these instances, mothers tended to be more receptive to the views of those who had a concrete, detailed understanding of their children, especially therapists and preschool teachers.

Nevertheless, mothers soon discovered that some professionals exert more influence than others over the transition to primary school. Especially where children were assessed as having an ID or challenging behaviours that made them a potential risk to be managed in the classroom, mothers had to acquiesce in a placement process controlled by key professionals in the education sector. Psychometric assessments were often crucial to this process of assessment and allocation. Certainly mothers negotiated outcomes but, in the main, they recognised that becoming more experienced ‘in the game’ did not make them ‘choosers’.

Mothers of children considered high functioning certainly exercised more choice, although they sometimes felt that they would have liked better access to autism-specific placements. Even though most of these women had to enrol their child in a mainstream school, some found that gatekeepers tried to block their entry. In these situations, the legislative requirement that each child has a right to attend their local government school operated as an

important brake on stigmatising actions. Often mothers retreated and went elsewhere when faced with stigmatising encounters. However, knowledge of this legislative guarantee allowed one mother in this sample to directly, and successfully, challenge the attempted exclusion of her son by his local school.

Lay knowledge, in the form of rumour and gossip, was also an important factor shaping primary school choice and placement for this sample. Indeed, the maternal autism grapevine was mentioned in almost two thirds of interviews. This knowledge, which I called ‘maternal talk’, travels through a largely female world of localised networks and is, I suggested, a crucial source of advice and warning that supplements and sometimes challenges professional guidance. Put simply, mothers listen to the advice of other mothers who share the same moral career. Because it is unofficial and experiential rumour is often considered more reliable than professional knowledge. Mothers, it is assumed, will ‘tell it like it is’.

While sociologists of education have provided many valuable insights into school choice and ‘hot knowledge’, I believe *Rumour has it* is the first publication that directly addresses the autism grapevine in relation to maternal decisions about, and negotiations around, school enrolment. Thematic analysis of the interviews showed that maternal talk had many different uses and effects. Sometimes it could be interpreted as a tactic of resistance to the official claims of professionals, especially where stories of injustice were aired and repeated. Mostly this ‘hot’ knowledge provided supplementary information about specific schools and a confirmation that the best decision or placement (whether mainstream or segregated) had been made.

Most vitally, I have suggested, maternal talk is crucial to the maintenance of identity in the moral community of ‘autism mothers’. This community has many divisions – mothers engage in their own allocation and placement processes as they identify primarily with the attitudes and advice of other mothers whose children are similarly situated on the autism spectrum. Thus, for example, mothers of children labelled ‘high functioning’ will primarily listen to other mothers whose children also have this label. However, an imagined broader community of all mothers whose children are diagnosed with autism formed an important reference point for individual mothers to think about their own situation and the future pathways that might open up or close down for their children. In this sense the heterogeneity of children diagnosed with autism, and the broad sweep of the diagnostic net, provides an encompassing set for processes of maternal comparison and contrast, which then feed into more immediate orientations and decisions.



Mothers devoted considerable energy and time advocating with education authorities on behalf of their children diagnosed with autism. Sometimes this maternal work was emotionally difficult. The need to highlight a child's impairments and inabilities as part of the process of extracting extra funding in the school system is a clear example of this. Mothers often spoke of these efforts as a 'battle', mobilising martial language to describe their actions. The willingness to engage in these battles was integral to women's sense of themselves as good mothers.

The publications *It's an absolute nightmare* and *Trading places* provide many examples of this advocacy work in relation to initial school enrolment and subsequent school change. All women engaged in this advocacy work, and were expected to do so by the education system. However, mothers with greater financial resources and confidence in their own professional capacities, largely achieved through their history of education and employment, were often able to provide greater support to their children and to negotiate their preferred school change outcomes through the tactical deployment of their own experts.

In *Trading places* I documented the fact that two of the mothers whose children attended government schools were either providing funds to pay for extra paraprofessional support or employing their own staff to work one-on-one with their child through much of the school day. This extra assistance was a considerable expense for these families. The NSW government commitment to devolving more decision-making power to local schools (Tovey, 2013) allows school flexibility in accepting extra support paid for by families of children diagnosed with autism.

The consequent class inequalities in the provision of services and support are, I suggest, a cause for concern and a surprising feature of the institutional practice of some government schools. Repeated government inquiries and reports have recommended that more resources are needed to make inclusive education a genuine possibility for children experiencing disability in NSW. These two cases point to the inadequacies of provision (why else would parents pay extra and schools accept that support?) and to the clear inequity of a situation in which the socioeconomic positioning of families may be an important determinant of the resources and supports a student receives, even in the government sector. Also of concern is the extent to which the provision of this continual one-on-one support (termed 'shadows' in the parlance of Applied Behaviour Analysis) may actually hinder the inclusion of students in the classroom.

Throughout this dissertation, I have attempted to balance a sense of the continued power of professionals to decide on and allocate places in the education system with an

acknowledgment of maternal agency. In doing so I have made use of de Certeau's (1984) distinction between strategies, linked with institutions and structures of power, and tactics, which he describes as an 'art of the weak'. Mothers' advocacy and mediation efforts or tactics occur within environments largely defined by the strategies of professionals and the institutions within which they are located (systems of therapy provision, educational assessment and schools).

I have largely avoided the language of 'resistance' because it tends, I think, to curtail efforts to think through some of the complexities of the interplay between bureaucracies, professional expertise, maternal advocacy and the experiences of students diagnosed with autism. As Sousa (2011) has pointed out the image of the resisting mother is part of a typification of all mothers of children experiencing disability as warrior-heroes fighting for social justice. This, it might be argued, is actually one aspect of wider circulating gendered ideologies of maternal responsibility for children's outcomes.

Although some of the women I interviewed presented themselves in a heroic mode, and had a strong sense of their ability to make changes to their children's lives, many did not. Some felt exhausted and confused. Others had difficulty either comprehending or making headway with school bureaucracies.

The tendency of theorists writing against the grain of medical frameworks that emphasise the burden of impairments is to applaud the resisting warrior-hero mother. While we need to acknowledge the extent of women's advocacy and mediation work, and the capacity of this work to promote positive changes, we also need to acknowledge the frequent difficulties of the lives of mothers of children diagnosed with autism and their intermittent sense of helplessness in the face of stigmatising and discriminatory institutional strategies.

### **The Moral Imperative to Care**

In this section I return to the main question posed in this research: *What kinds of care, both pragmatic and affective, are mothers engaged in as they negotiate the transition to primary school of children diagnosed with autism?*

All of the publications that comprise this dissertation have highlighted the intensive maternal labour required by the transition to primary school. Other research has underlined the extent of this labour for all mothers. However, I have argued throughout that these demands are particularly intensive when mothers have children experiencing disability. This observation finds a great deal of support in the relevant literature on mothering and disability (e.g. Runswick-Cole,

2008; Wilkinson, 1996). Once a child is suspected of having impairments, families are caught up in systems of childhood surveillance that codify those impairments into diagnoses and which then calibrate the levels of support that will be offered by the state to these children, including therapy and education.

Mothers need to engage with these systems of surveillance/support and to assess the different knowledge claims made by professionals and other mothers. This engagement requires substantial maternal labour in the form of research, mediation and advocacy. In the particular case of autism, the heterogeneity of children captured by diagnosis as well as the existence of many competing therapies that promise the partial remediation of deficits, means that women have a lot to take in and decide on. Once mothers have passed through the stages of diagnosis and early intervention, they embark on a new phase of their moral careers – they become mothers of schoolchildren diagnosed with autism. Now they need to find out about the complex system of education service provision, to juggle the advice of various professionals and to listen to what other families have to say about their experiences. Sometimes, too, they must face stigmatising encounters.

All of the mothers who participated in this research engaged in tactical manoeuvres to achieve what they saw as good outcomes for their children. They did this in the midst of entrenched disabling ideologies and practices, which produced exclusionary strategies. Their main focus was on the emotional wellbeing of their children. Most had little interest in the idea of inclusive education; in fact, many had never even heard the phrase. They all accepted the necessity for a continuum of education placements, even when their own children were doing well in mainstream schools.

Mothers were certainly, at times, vocal critics, aware of many of the injustices being faced by their children and themselves. But this criticism was usually directed at very specific targets and localised disabling practices. Inclusion, as many commentators have pointed out, is an ongoing process. Women will only enrol children in regular classes in mainstream schools if they are satisfied that they will receive the attention they need, the resources to help them flourish and are likely to be free of stigmatisation. Where children have more pronounced support needs, mothers often feel that, in current circumstances, this can only be achieved in segregated settings, either support classes or special schools. Professionals frequently encourage this conclusion.

Taken together, the publications in this dissertation attest to the pressure exerted on women to conform to ‘good’ mothering standards within the context of raising children

diagnosed with autism. The predominant cultural image of a good mother of a child experiencing disability is of a woman who is selflessly dedicated to improving her child and to advocating for services and resources. While this image of the self-sacrifice demanded by the maternal role has been criticised in the disability rights community as perpetuating negative stereotypes of burden and dependency (see Ryan & Runswick-Cole, 2008; Sousa, 2011), many women continue to feel that it is almost entirely up to them to help their child.

As noted in this sample, they also usually find that the extent of their caring commitments means they are either unable to work or can only work part-time. They also know that these commitments are unlikely to lessen over time. In these circumstances, it is hardly surprising that women often do their best to embrace ‘special needs’ parenting as an ethical vocation rather than as a diminishment of familial opportunities traced out in the horizon of a differently imagined future.

The mothers interviewed for this research generally saw one of their primary responsibilities as accessing the services and therapies that might assist their child to overcome impairments, including education placements. In doing so, they sometimes aligned their perspectives with a medicalised deficit model of autism. But mothers also insisted on the full personhood of their children (Landsman, 2009) and advocated for others to respect their child’s differences and preferences. In the course of reflecting on stigmatisation and exclusion, these women often articulated a cogent understanding of the ways in which social attitudes about individuals with impairments contribute to disabling actions and contexts.

I began this Discussion with a quote from philosopher Martha Nussbaum who has thought deeply on the issues of disability, social justice and care. She reminds her readers of the importance of respecting the very real work involved in care, ‘to spend money on it and deliberate seriously about it as a public issue’ (Nussbaum, 2006, p. 214). The mothers who generously agreed to be interviewed for this research often felt that the demands of their care were not fully acknowledged and that the substantial competencies they developed were undervalued. They also often felt that they and their children were subject to stigmatising attitudes and discriminatory practices.

The lives of all mothers and their children are interlinked. For mothers of children with diagnosed disabilities this is especially the case. The intensified needs for support and advocacy of children experiencing disability, including autism, as well as the social expectation that mothers will take on almost all of the pragmatic and affective care needed, has been a recurring

theme of this dissertation. Stigmatising attitudes and exclusionary practices towards students diagnosed with autism add substantially to the work of mothers, who are often engaged in mediation and advocacy that seeks to achieve more equitable outcomes for their children. The forms of systemic discrimination documented here have substantial emotional costs for women.

Autism has profound implications for the careers of students and their mothers. Those careers are shaped by processes of stereotyping, stigmatisation and exclusion that do not spring from the repercussions of neurodevelopmental impairment. Rather, they are constructed by the ongoing situated practices and interactions between all of those operating within the autism matrix – professionals, families and diagnosed individuals.

My hope is that in sharing the narratives of mothers this dissertation makes a contribution to understanding some of the mechanisms of education exclusion, as well as the difficulties experienced by students diagnosed with autism and their families in NSW. Comprehending the extent of Autism Inclusion Disorder (Chapter 8) is one foundational step in working towards an inclusive education, as well as a more sympathetic and responsive context for mothers of students placed on the spectrum.

### **Limitations and Directions**

The methodology used in this research is qualitative. The small sample size (22 families) was necessitated by the qualitative approach adopted. Conducting multiple semi-structured interviews with participants over a three-year period, creating and checking transcripts, as well as using narrative analysis to thematically organise and interpret the material, is a time consuming and intensive process. The sample size does, to some extent, limit my ability to make broad generalisations from the research findings.

However, the use of purposive sampling did allow access to mothers of students located across the entire range of the autism spectrum who were enrolled in all of the available settings in the NSW education system (special schools, support classes and regular classes in mainstream schools) as well as in all market sectors of this system (government, Catholic and Independent). The sample does, therefore, allow informed commentary and analysis of many aspects of the system of education service provision for students diagnosed with autism in NSW, as reported by mothers.

Further, as mentioned earlier in this Discussion, many of the findings from this study have been confirmed by the findings of other studies. This consistency suggests that the research sheds

light on wider patterns and practices in NSW. For example, the finding of a drift towards segregated settings for students diagnosed with autism has been confirmed by other research, which documents the same process with students who have various disability and mental health labels in NSW (Graham & Sweller, 2011).

During the period of this research multiple government inquiries and reviews were conducted, in NSW and nationally, into the education for students experiencing disability. These inquiries and reviews have also provided frequent confirmation of the disabling attitudes and practices analysed in this dissertation, as well as of the extensive maternal work created by these. This disabling context for students and families is amply documented in the 2010 *Inquiry into provision of education to students with a disability or special needs* (NSW Parliament, 2010), the 2012 *Inquiry into transition support for students with additional or complex needs and their families* (NSW Parliament, 2012) and the 2012 *Report on the Review of Disability Standards for Education 2005* (DEEWR, 2012). These are all part of the public record. Indeed, the resonance between my research findings and those of other scholars, as well as of government inquiries and reviews, creates reasonable confidence that many of the events and processes described by the 22 mothers participating in this research are representative of the experiences of many families of students experiencing disability.

This research has focused on mothers. I have repeatedly outlined the reasons for this, including the fact that women actually do most of the work of school choice and school placement, especially in the primary school years. Overall the participating mothers were a diverse group across a number of indicators, including socio-economic position, ethnicity and education. But the sample was skewed towards more affluent and more educated women. Women volunteered to participate and it may be that mothers with a higher socioeconomic positioning were more comfortable speaking with a university researcher and more likely to see the potential value in doing so.

Research investigating the experience of more mothers from varying socioeconomic positions would allow insight into notions of mothering and disability operative across different class locations.<sup>12</sup> Further study of women from a greater variety of cultural groupings would also yield better understanding of the ways in which ethnicity interacts with disability and mothering.

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<sup>12</sup> From a broader knowledge of the intersections between class and educational experience it seems very unlikely, however, that less privileged women and their children would be less subject to the mechanisms of sorting, stigmatisation and exclusion outlined in this dissertation.

Given the increasingly multicultural composition of Australian society this is a vastly under-researched topic.

Investigating the points of view of other family members would also create a fuller picture and provide an interesting base for comparison and contrast. Most obviously, the role of fathers could be researched. This would allow an investigation into how fathers see their role in family life and into current patterns of parenting and care, and the intersection of these with ideologies of masculinity. More generally, recent calls for family-focused autism spectrum disorder research underline the value of capturing multiple perspectives within families as part of a holistic approach to service planning and provision (Cridland, Jones, Magee, & Caputi, 2014).

Perhaps most importantly, research that more directly represents the viewpoint and experiences of students experiencing disability is vital. In the case of students diagnosed with autism, this presents challenges, especially in relation to communicative impairment as a diagnostic feature. Finding ways of engaging young people experiencing disability in research on school transition requires some creative thinking about methods. Some research has addressed the perceptions and experiences of students diagnosed with autism in relation to school but, due to these methodological difficulties, it has largely been concentrated on individuals labelled with high functioning autism or Asperger's (e.g. Carrington and Graham, 2001; Carrington, Papinczak, & Templeton, 2003; Carrington, Templeton, & Papinczak, 2003; Humphrey & Lewis, 2008). The use of ethnographic observations and video recordings of quotidian classroom and playground activities in a study of the social realities of inclusion of students labeled with HFA in public schools in the United States is of particular methodological interest in this regard (Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001).

Clearly the perspective of professionals involved in the sorting and streaming process as well as school gatekeepers and primary school educators would provide a counterbalance to maternal perspectives. It would also reveal more about both the bureaucratic mechanisms through which students diagnosed with autism continue to be streamed and some of the perceptions leading to stigmatisation and exclusion. A number of scholars have undertaken research in this area both in relation to disability generally (e.g. Graham & Spandagou, 2011) and autism more specifically (e.g. Helps, Newsom-Davis, & Callias, 1999; Horrocks, White, & Roberts, 2008). Most of the literature on inclusion is, however, pedagogically oriented, suggesting and evaluating ways of better engaging learners on the autism spectrum with classroom activities and academic tasks (e.g. Simpson, de Boer-Ott, & Smith-Myles, 2003). My focus has, by contrast, been on

education exclusion/inclusion as a set of practices generated by ongoing tensions between integrationist and inclusive understandings, which are often inflected by negative stereotypes of students diagnosed with autism.

This dissertation has drawn on a longitudinal research design. This has allowed some insight into processes of school change and shifting maternal attitudes. Three years is, however, only a brief window. Most autism research is heavily concentrated in the early childhood years, especially on identification, assessments and treatments. As many parents ruefully note, interest in children diagnosed with autism tends to diminish sharply with age. By the time students on the spectrum reach adolescence many are no longer receiving specialised services, with studies consistently pointing to large areas of unmet need for young adults and their families (e.g. Eaves & Ho, 2008).

We know little about the lives of these young people and their families. However, the few follow-up studies undertaken have found that most adults diagnosed with autism remain very dependent on their families (Howlin, Goode, Hutton, & Rutter, 2004) with either limited or no employment (Autism Spectrum Australia, 2012). More fine-grained research is needed into the unfolding careers of children diagnosed with autism and their carers across the lifespan. Gray's (2002) longitudinal study of Australian families of children with autism is one of the few exemplars of this approach.

Following the families who participated in this research would give insight into both student and maternal careers as they unfold across time. The cohort of children in this study is growing up during a time of greater emphasis on inclusion and on the rights of all individuals experiencing disability to be accepted as valued members of society. How will the changing contexts of social attitudes constructing disability impact on these individuals and their families in the coming years?

Many other questions could also be addressed. Will those who were at the margins of the diagnostic spread of autism under DSM-IV lose their label, or be categorised with other disorders? Will the outcomes for children labelled high functioning or Asperger's be substantially better in terms of educational attainment and social relationships? In the very near future, a study of the transition to secondary school for these students, occurring for most in 2017, would be valuable in tracking continuities and changes in education provision and familial experiences.

More immediately, much of the vast body of interview material collected for this research awaits further analysis. Many of the recurring themes of these maternal narratives, and the



broader topics they suggested, could not be fitted into this dissertation. This includes extensive narratives about diagnosis, psychometric assessments, efforts to navigate the tricky terrain of early intervention and, perhaps of most interest to this author, the impact of these experiences on women's identity. These mothers also told me many stories about their child's experiences of school, their own relationships with other mothers and the politics of playground disclosure that deserve analytic attention.

Much has been written about the vast range of therapies and treatments parents of children diagnosed with autism try to make sense of (Lilley, 2011b; Prior, Roberts, Rodger & Williams, 2011; Silverman, 2013). All of the families participating in this study were engaged with various forms of early intervention, some of which have widespread professional validation (such as speech and occupational therapy) and others considered more fringe or experimental (such as special dietary regimes or chiropractic care). Some of the families also invested considerable time and money in more intensive interventions, particularly Applied Behaviour Analysis and Relationships Development Intervention. The connections between age of diagnosis, identification of intellectual disability, provision of therapies and the social class of parents is of great interest to practitioners and researchers (e.g., Bhasin & Schendel, 2007; Pinborough-Zimmerman et al., 2011). Although this research is concentrated on the period of primary school transition, the topic of early intervention was included in interview schedules. Thus the data set contains material pertinent to these issues. Further analysis of this topic deserves attention in future publications arising from this data.

The divide between students diagnosed with autism and those who also have a concurrent diagnosis of ID has been a persistent theme in this dissertation. In the process of conducting interviews over three years I became aware that the experiences of mothers whose children were categorised as intellectually disabled were often very different to women whose children were labelled 'high functioning'. The kinds of intensive care required by children diagnosed with ID and autism, and the implications of those demands for mothers, made the lives of these families and their expectations for the future qualitatively different. As Eyal and colleagues (2010, p. 6) have argued, the categories of autism and ID 'have rearranged in relation to one another over the span of little more than half a century'. Once again, further analysis of that rearrangement and of women's response to concurrent diagnoses, as they struggle to claim the future potential and the full personhood of their children, will be a fruitful area for future publication.

The processes of school choice and change, as narrated by mothers in this study, provide a detailed picture of the concrete ways in which school inclusion and exclusion are forged in practice. Many of the difficulties and points of conflict between families and education professionals, as well as mechanisms of exclusion, documented in NSW apply more generally to places and contexts where the principles and practices of inclusive education have not gained full acceptance and the specter of autism continues to elicit negative and stereotypical responses from some school gatekeepers and educators.

Attitudes towards individuals with impairments have changed a great deal in the last forty years. Prior to the general acceptance of the principle of 'normalisation' in the 1970s, people experiencing disability were often segregated in institutions or lived fairly sequestered and limited lives within families (Forlin, 2006; PricewaterhouseCoopers, 2011). Current arguments about the rights of all students to attend regular classes in mainstream schools versus the value of continuing to provide special schools and support classes, specifically designed to cater to the needs of students diagnosed with disabilities, can be understood as part of a relatively recent history of desegregation. At the moment, Australian legislation provides clear support for inclusion across many sectors of service provision, including education. Nevertheless the implementation of this legislation, as well as community support for it, remains inconsistent (Stancliffe, 2012).

In fact, segregated services for adults experiencing disability are still common, including the provision of day programs (segregated employment) and group homes (segregated living) (Stancliffe, 2012). In NSW some large residential centres were only closed as recently as 2010 (Fisher et al., 2013). Person-centred approaches to disability support are gradually being implemented, but this is, in many senses, an experimental process requiring different models and strategies to undo the congregation of services governing disability without removing needed support for individuals living with impairments. The National Disability Insurance Scheme currently being trialled in Australia is explicitly conceived as part of this undoing (PricewaterhouseCoopers, 2011).

Arguments about the provision of education for students diagnosed with autism provide a clear illustration of the ongoing tensions between normalisation and inclusion in current education policy and practice. There is general acceptance amongst professionals that children placed at the upper end of the autism spectrum can, and should, be part of regular classrooms. However, there remains a widespread view that those with more severe autistic traits and/or with

a concurrent diagnosis of intellectual disability will have their needs better met in segregated settings (Chapter 6). The notion that students should be directed in and out of segregated provision based on their individual capacities belongs firmly to the philosophy of integration, which is tied to the goal of normalisation. By contrast, the goal of inclusion, which has emerged from the demands of the disability rights movement of the 1990s, offers a far more radical vision of the removal of all forms of segregated provision (Cologon, 2013; Culham & Nind, 2003).

There are many ways in which the goals of inclusive education can be better realised in Australia. As noted throughout this dissertation, the Disability Standards for Education 2005 are an important mechanism for achieving a more inclusive education system, providing a framework to ensure that students with impairments are able to access and participate in education on the same basis as other students. As the 2012 review of the Standards found there are, at the moment, few consequences for education providers who breach these requirements. The lack of accountability for compliance with the Standards, as well as the complexity of the complaints process, were named as areas needing reform. Where complaints are pursued, the outcomes of many grievances are suppressed as part of settlement (DEEWR, 2012). In this situation, detailed, qualitative research is one important way of contributing to our knowledge about the experience of education for students experiencing disability and their families.

From 2015 all schools in Australia will be required to participate annually in the Nationally Consistent Collection of Data on School Students with Disability. This will give governments, schools and education authorities information about how many students diagnosed with disabilities are enrolled in Australian schools, where they are located and the level of adjustments provided for them to participate in schooling on the same basis as other students. Data will be used to gain a clearer picture of the needs of students experiencing disability, and give more support to schools so that they can better understand and implement their core responsibilities under the *Disability Discrimination Act 1992* and the Disability Standards for Education 2005 (Australian Government, 2013). This data will also provide a rich resource for future research.

The job of making mainstream services accessible to everyone and ‘attuned to the depth of diversity in our society’ (PricewaterhouseCoopers, 2011, p. 18), including people experiencing disability, is a large one. Compliance with legislation promoting social justice for all Australians is one aspect of this endeavour. Shifts in attitudes and expectations are another. Contributing to the fund of knowledge about continuing practices of exclusion, including the meaning frames

within which those practices are located and contested, is important because it directs attention to the tensions and points of conflict within the current education landscape. Understanding more about the experiences of students diagnosed with autism and their families as they encounter formal education for the first time is one perspective on the much wider issue of achieving a more inclusive education for all students.

### **Drawing Connections**

The flyer for this study featured a drawing of a mother and child holding hands (Appendix 2). My son drew this when he was four years old while attending therapy sessions with an early childhood special educator. I chose the picture partly because I thought it might appeal to other mothers. Instead of the focus on deficits, so common to autism research, I hoped the drawing would help to quickly sketch the centrality of the mother/child relationship and my commitment to representing the perspectives of families.

For me the drawing had an extra layer of meaning. Because it is my son's graphic depiction of our joined relationship it gives me hope for our affective present and future. Given the suggestion in much expert writing about autism of lack of empathy, of treating people as if they are merely furniture, of an inability to forge deep human connections (see Kennett, 2002; Krahn & Fenton 2009), the drawing stands as a small challenge to such monolithic certitudes.

I mentioned that when I began this PhD in 2009 my son was attending an autism-specific support class. He had moved there from a special school. In 2010 I withdrew him from the support class and enrolled him at our local primary school. Our family has, therefore, experienced both segregated and mainstream options in the Independent and the government sectors of education provision in NSW.

I have found a strong congruence between the inclusive education literature and our personal experiences of the benefits of moving our son to the local primary school and, in 2014, our local government secondary school. I also understand, from first-hand experience, that making education 'choices' for children diagnosed with autism is a hard road that takes many twists and turns. There remain many barriers to the achievement of inclusive education. Throughout this dissertation my critique is simultaneously aimed at the system of education provision in NSW, the informal practices and attitudes that create exclusionary environments, the ongoing stigmatisation of children and their families, and the gendered ideologies that continue to make mothers feel culpable and inadequate.

A good friend of mine who is a teacher remarked that my publications were very difficult for her to read. She felt they were hard on educators. I certainly acknowledge the good and the dedicated work many teachers and other professionals do. Indeed, our family's experience in the government system has largely been very positive. Nevertheless the stories mothers told me often cast a negative light on some professionals, bureaucrats, gatekeepers, teachers or schools.

More importantly, they pointed to the systemic nature of educational exclusion for children diagnosed with autism in NSW. These stories also speak of the strain, caused by socially devaluing attitudes and intensified caring demands, of being the mother of a child who is perceived to be different from the norm. The uncomfortable quality of these maternal narratives is, I suggest, all the more reason they need to be told.

### **Summary and Conclusion**

The simultaneous existence of government commitments to inclusive education alongside the provision of a continuum of placements creates a complex field of school choice and placement in NSW. Mothers, who do most of the work of negotiating primary school transition, must familiarise themselves with this complex field as they advocate for their children. Students diagnosed with autism in NSW continue to be sorted into streams by professionals, according to judgments about their (in)abilities. In this sample of 22 families, those students who had a concurrent diagnosis of intellectual disability were all enrolled in support classes or special schools. Conversely, most of the students labelled 'high functioning' autism were enrolled in regular classes in mainstream schools. Students labelled 'borderline' presented the greatest challenge to the sorting processes of professionals.

There was a high level of school change (40%) in the first two years of primary school for these students. Mothers reported that these changes largely occurred in response to student distress prompted by disabling educator attitudes and practices. School change generally reinforced the role of segregated education, as mothers mainly moved their children from mainstream schools to support classes or special schools. However, some mothers described their children as experiencing forms of micro-exclusion even in segregated settings.

Professional guidance and rumour were important sources of knowledge about schooling for this sample. Women generally felt less powerful than professionals in the placement process. Nevertheless, they were often actively engaged in the transition to school and in school change. In the process of this engagement, maternal tactics sometimes successfully challenged

institutional strategies. Rumour, in particular, provided opportunities to air injustice and present a different viewpoint to that of professionals, as well as contributing to a sense of shared identity among mothers.

Both children diagnosed with autism and their mothers were frequently stigmatised by school gatekeepers, especially in mainstream schools. These stigmatising encounters impacted negatively on the emotional wellbeing of women. This impact was related, I argued, to the experience of mother/child intersubjectivity, forged through prolonged dependency and gendered ideologies of maternal culpability.

Mothers played a crucial role in mediating between children and schools, as well as advocating for their sons and daughters. This advocacy was particularly strenuous in cases of school change. Families with more resources were sometimes able to achieve higher levels of support and different outcomes for their children. It therefore appears from this sample that there are some socioeconomic inequalities in access to education, even in government schools.

Mothers were expected to provide intensive levels of pragmatic and affective care in the course of primary school transition. In doing so, they were influenced by gendered ideologies of good mothering as an encompassing ethical vocation. This ideology is especially potent when mothers care for children experiencing disability. Mothers develop a vast range of competencies and skills as part of this caring role, but these remain undervalued in the education system.

Overall, the impact of inclusive education was limited for this sample. Ongoing practices of sorting and streaming according to student characteristics suggest that older models of integration, not inclusion, are still operating in NSW.

This dissertation has addressed some of the intersections between frames of knowledge, processes of sorting, forms of stigmatisation and expectations of maternal care. Throughout I have suggested that ideologies of appropriate mothering are intertwined with accepting the legitimacy of calibrating potential futures through student streaming.

Pervasive practices of stigmatisation and exclusion directed towards students diagnosed with autism were documented on the basis of maternal report. Operating within this disabling context has, I suggest, negative consequences for both mothers and their children. Listening to these mothers contributes to the social fund of knowledge about current education practices in NSW impacting on children experiencing disability and their families. That knowledge, in turn, is part of the work needed to help us all to imagine different, and more inclusive, futures.

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## **Appendix 1**

### **Ethics Approvals**

- A) *Ethics approval Macquarie University* (30 November 2009)
- B) *Ethics approval Autism Spectrum Australia* (2 December 2009)





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30 November 2009

Ms Rozanna Lilley  
98 Westbourne Street  
Petersham  
NSW 2049

Reference: HE27NOV2009-D00187

Dear Ms Lilley

### FINAL APPROVAL

**Title of project:** *Maternal Transitions: When Children with Autism Start Primary School*

Interim Approval of the above application was granted by the Executive of the Ethics Review Committee (Human Research) on 04 November 2009. This Interim Approval was reviewed by the full Committee at its meeting on 27 November 2009 and was ratified.

Please note the following standard requirements of approval:

1. The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Human Research (2007)*.
2. Approval will be for a period of five (5) years subject to the provision of annual reports. **Your first progress report is due on 04 November 2010.**

If you complete the work earlier than you had planned you must submit a Final Report as soon as the work is completed. If the project has been discontinued or not commenced for any reason, you are also required to submit a Final Report on the project.

Progress Reports and Final Reports are available at the following website:  
[http://www.research.mq.edu.au/researchers/ethics/human\\_ethics/forms](http://www.research.mq.edu.au/researchers/ethics/human_ethics/forms)

3. If the project has run for more than five (5) years you cannot renew approval for the project. You will need to complete and submit a Final Report and submit a new application for the project. (The five year limit on renewal of approvals allows the Committee to fully re-review research in an environment where legislation, guidelines and requirements are continually changing, for example, new child protection and privacy laws).
4. Please notify the Committee of any amendment to the project.
5. Please notify the Committee immediately in the event of any adverse effects on participants or of any unforeseen events that might affect continued ethical acceptability of the project.

6. At all times you are responsible for the ethical conduct of your research in accordance with the guidelines established by the University. This information is available at:  
<http://www.research.mq.edu.au/policy>

If you will be applying for or have applied for internal or external funding for the above project it is your responsibility to provide Macquarie University's Research Grants Officer with a copy of this letter as soon as possible. The Research Grants Officer will not inform external funding agencies that you have final approval for your project and funds will not be released until the Research Grants Officer has received a copy of this final approval letter.

Yours sincerely

---

Dr Karolyn White  
Director of Research Ethics  
Chair, Ethics Review Committee (Human Research)

On Tue, 2 Dec 2009 12:37:54 +1100, "Debra Costley"  
<[dcostley@autismspectrum.org.au](mailto:dcostley@autismspectrum.org.au)> said:

Dear Rose,

Thank you very much for addressing the minor points in our letter to you.  
Please consider this email as confirmation that your research is approved  
by the Aspect Research Ethics Committee.

If you have a flier or information leaflet that you would like us to  
place on our website please forward it to me and I will arrange for it  
to be uploaded.

With thanks  
Debra

Dr. Debra Costley  
Director, Education Development & Research,  
Autism Spectrum Australia.

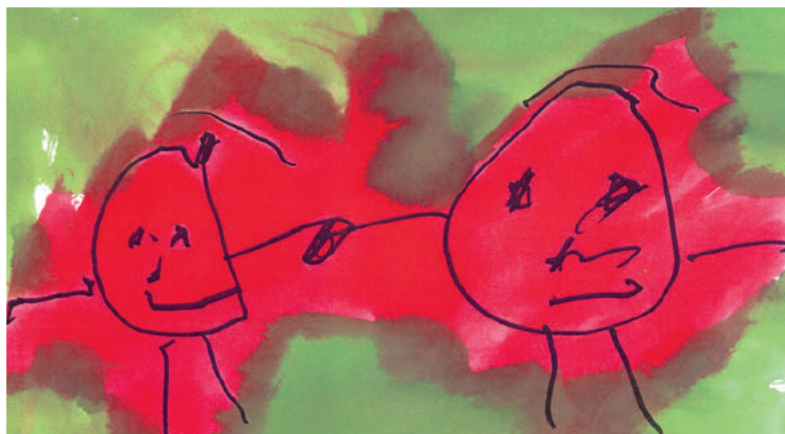


## **Appendix 2**

### **Recruitment flyer**

This flyer was distributed via email to early intervention providers, support groups for parents of children diagnosed with autism and also placed on the Autism Spectrum Australia website.





## Maternal Transitions: When Children with Autism Start Primary School

- Does your child have a previous diagnosis of an Autism Spectrum Disorder?
- Is your child starting primary school next year?
- Are you enrolling your child in either a special school, support class or a regular class?

If you answered **yes** to the above questions, you are invited to take part in this research study.

### The study

This study is being conducted as part of my PhD research at Macquarie University and aims to explore the experiences of mothers as their children with an ASD diagnosis start primary school. The information obtained from this study will add to our understanding of family life, schooling and ASD in NSW. It may also help education stakeholders in their planning.

### Who can participate?

I am seeking mothers of children who have a previous diagnosis of Autism Spectrum Disorder (i.e. Aspergers, Autism, PDD) who are starting primary school in 2010.

### What will it involve?

Participation in the study will involve three interviews – one in 2009, one in 2010 and a final one in 2011. Each interview will last approximately one hour. It will be recorded and transcribed. You will be asked about a range of topics including your experiences of early intervention, your child's transition to primary school, the supports available to your child at school and your involvement with the school community.

You are free to withdraw from the study whenever you wish. Participation or withdrawal will not affect any services received by you or your child.

### Who is the investigator?

Rozanna Lilley, a PhD candidate at the Children and Families Research Centre, Macquarie University.

### How can you contact me?

If you would like to participate or if you would like more information regarding this study, you can contact Rozanna on (02) 9590 3721 or email her on [roselilley@fastmail.fm](mailto:roselilley@fastmail.fm)







### **Appendix 3**

#### **Interview Information Statement and Schedule**

- A) *Information statement with participant consent form*
- B) *Interview schedule*
- C) *Interview three amended schedule emailed to participants in 2011*



### Information and Consent Form

#### ***Maternal Transitions: When Children with Autism Start Primary School***

You are invited to participate in a study investigating the experiences of mothers whose children with autism are transitioning to primary school in New South Wales. The purpose of the study is to find out what kinds of care mothers provide to help their children and the effects of different educational settings on family life. The study is being conducted by Rozanna Lilley. Rozanna can be contacted on either 95903721 (preferred) or 0417735601. Rozanna's email address is [roselilley@fastmail.fm](mailto:roselilley@fastmail.fm). This study is being conducted to fulfil the requirements of a PhD in Early Childhood under the supervision of Professor Jennifer Bowes, Director of the Children and Families Research Centre, Institute of Early Childhood, Macquarie University. Jennifer can be contacted on 98509844. Jennifer's email address is [jennifer.bowes@aces.mq.edu.au](mailto:jennifer.bowes@aces.mq.edu.au).

If you decide to participate, you will be interviewed three times—before your child starts school, when your child is in Kindergarten and when your child is in Year 1. Each interview will last approximately one hour. In the first interview, topics discussed will include your experiences of autism diagnosis, early intervention and school placement. In the second and third interviews, topics will include your child's experience of school, any changes to family life during this transition period, the extent of support you have received, as well as your relationship with school personnel and the wider school community. You will also be asked about your attitude to educational inclusion.

All interviews will be recorded and then transcribed. You will be given the opportunity to read the transcripts to see if you would like any of your comments removed. While many mothers will feel comfortable with talking about themselves, their families and their child, some may feel distressed when discussing topics such as autism diagnosis or schooling. You need to bear this in mind when thinking about whether or not you are comfortable with being interviewed. If you do feel distressed following the interviews, there are a number of organisations offering advice or counselling to mothers of children with a diagnosis of autism spectrum disorder who you could contact. These services include the Aspect Autism Infoline (1800 069 978) and Carers NSW (1800 242 636). Alternatively, you may wish to consult your GP.

Any information or personal details gathered in the course of this study are confidential (except as required by law). No individual will be identified in any publication of the results. Other potentially identifying information will also be altered, including names and locations of early intervention services or schools. Only Rozanna will have full access to the data, which will be

stored in a password-protected computer. Jennifer will have access to the edited transcripts with all identifying information removed.

The transcripts for these interviews will form the basis for a number of different journal articles. In addition, I may use this material in academic books and/or books intended for parents and autism or education professionals. Publications will not include any information identifying individual participants. All interview participants will be sent a written summary of findings at the conclusion of the project and Rozanna will include links to any material published as a result of the research on her Macquarie University web page.

Participation in this study is entirely voluntary; you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Your decision about whether or not to participate will in no way affect any of the services you receive or your relationships with any early intervention providers or schools.

I, \_\_\_\_\_, have read and understood the information above, and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw at any time. I have been given a copy of this form to keep.

Participant's Name: \_\_\_\_\_ (block letters)

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigator's Name: \_\_\_\_\_ (block letters)

Investigator's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

The ethical aspects of this study have been approved by the Macquarie University Ethics Review Committee (Human Research). If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Ethics Review Committee through the Director, Research Ethics (telephone 9850 7854; email [ethics@mq.edu.au](mailto:ethics@mq.edu.au)). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

***Maternal Transitions: When Children with Autism Start Primary School***

Thank you for your interest in the *Maternal Transitions* research project. Participants will be interviewed three times (once in 2009, once in 2010 and once in 2011). Each interview will last approximately sixty minutes. All interviews will be recorded and transcribed. You will have the opportunity to edit the transcription of each of your interviews.

**Interview Schedule**

This document contains a list of the questions I will ask you in each interview. It will also give you a good idea of the topics to be covered. Please note that this is intended as a guide only. If you would prefer not to talk about any of these issues or have any concerns about these questions please let me know. You are free to not comment on any of these questions. Your participation in the project is voluntary and you may withdraw at any time without any consequences.

***Interview one*** will take place in 2009, a few months prior to primary school transition. Topics discussed will include experiences of diagnosis, early intervention, and processes of school placement. Questions will include:

1. What were the circumstances leading to your child's diagnosis? How did you feel about diagnosis at the time? How do you feel about diagnosis now?
2. Has your child had any early intervention? If so, what types of early intervention? How helpful do you think early intervention has been? How involved have you been in early intervention?
3. When you were pregnant with this child, what did you imagine being a mother would be like? What were your hopes and dreams for your child? How different is your experience of mothering now compared to what you previously imagined?
4. What kinds of changes have you seen in your child since diagnosis? To what extent do you attribute those changes to early intervention?
5. What was your role in the process of deciding where your child would go to school? How many different schools did you visit? How much information did you receive about schooling for your child? What kinds of advice were you given about the best sort of school for your child? Do you feel you had a choice of schooling options?
6. Describe the process of school placement. Did you see a disability programs consultant? If so, what did they do for you?
7. Did you have a meeting at the school about your child's level of support needs? Who attended the meeting? How do you feel about the meeting? What kinds of educational services and resources do you think your child will get? Do you think it will be enough?

8. How was your child supported in their transition from their early childhood setting to school? Do you think the transition was well planned? Do you think it will help your child settle into school?
9. Will having your child at school change your day much? Do you think you will have much involvement with your child's school? Are you thinking about going back to work?
10. What areas of school life are you most concerned about for your child? What do you hope your child will achieve in their first year of school?
11. What do you think 'school inclusion' means? What are your views about school inclusion? Do you think your child's school is inclusive?

**Interview two** will take place in 2010, once your child has settled into their Kindergarten year. The focus here is on home-school collaboration ('partnership'), negotiating with school personnel and the extent of your family's integration into your school community. Topics will include your child's experience of school, the changes to your family life during this transition period, the extent of support you have received, as well as your relationship with school personnel and the wider school community. Questions asked will include:

1. How has your child settled into Kindergarten? Do you think the transition to school strategies were successful?
2. How does the school communicate with you? What ongoing communication is available between you and the class teacher? Do you talk with anyone at the school about your child's progress? How frequently? Do you feel involved in decisions relating to your child's education?
3. Are you involved with the school? If so, how? Do you help in the classroom or with fundraising or other activities? If so, do you enjoy this? What benefits does it have? What are the drawbacks?
4. What kinds of contacts do you have with other children and parents at the school? Do you count any of the parents as friends?
5. Does your role, as a mother, seem very different to how it was before your child started school? Is there a different level of involvement? What kinds of daily help do you still need to give to your child? Is your child becoming more independent?
6. What kinds of educational services and resources does your child get? How adequate are these? Does your child have an Individual Education Plan (IEP)? If so, do you think the IEP benefits them? Were you consulted about the IEP? If your child has a learning support officer (LSO), describe what this person does with your child and with your child's class. What is your relationship like with the LSO? How important is the LSO to your child?
7. Is your child happy at school? Does the teacher understand your child? Have you had any particular concerns? Have you heard about or witnessed any bullying?
8. How is your child when they come home from school? How hard is it to get your child to go to school? What do you want your child to get out of education?
9. How integrated into the life of the school is your child? Do you feel welcome at the school?
10. Do you feel that your child is in the best educational setting available for them? What do you hope your child will achieve at school in the next year? Do you anticipate any major changes in your activities with your child and your child's school over the course of the next six months?
11. What do you think school inclusion means? What are your views about school inclusion? Do you think your child's school is inclusive?

***Interview three*** will take place in 2011, when the child is in Grade One. This interview will follow essentially the same format as interview two, in addition to asking about any changes in school placement and the reasons for these.

*Interview three amended schedule emailed to participants in 2011*

**Interview three** will take place in 2011/2012. The focus here is on home-school collaboration ('partnership'), negotiating with school personnel and the extent of your family's integration into your school community. Topics will include your child's experience of school, the changes to your family life during this period, the extent of support you have received, as well as your relationship with school personnel and the wider school community. Questions asked will include:

12. How has the school year been overall for your child? Do you feel that they are settled in their current school?
13. How does the school communicate with you? What ongoing communication is available between you and the class teacher? Do you talk with anyone at the school about your child's progress? How frequently? Do you feel involved in decisions relating to your child's education?
14. Are you involved with the school? If so, how? Do you help in the classroom or with fundraising or other activities? If so, do you enjoy this? What benefits does it have? What are the drawbacks?
15. What kinds of contacts do you have with other children and parents at the school? Do you count any of the parents as friends?
16. Does your role, as a mother, seem very different to how it was before your child started school? Is there a different level of involvement? What kinds of daily help do you still need to give to your child? Is your child becoming more independent?
17. To what extent is your mothering style similar to, or different from, the way you were brought up?
18. What kinds of educational services and resources does your child get? How adequate are these? Does your child have an Individual education Plan (IEP)? If so, do you think the IEP benefits them? Were you consulted about the IEP? If your child has a learning support officer (LSO), describe what this person does with your child and with your child's class. What is your relationship like with the LSO? How important is the LSO to your child?
19. Is your child happy at school? Does the teacher understand your child? Have you had any particular concerns? Have you heard about or witnessed any bullying?
20. How is your child when they come home from school? How hard is it to get your child to go to school? What do you want your child to get out of education?
21. How integrated into the life of the school is your child? Do you feel welcome at the school?
22. Do you feel that your child is in the best educational setting available for them? What do you hope your child will achieve at school in the next year? Do you anticipate any major changes in your activities with your child and your child's school over the course of the next six months?
23. What do you think school inclusion means? What are your views about school inclusion? Do you think your child's school is inclusive?



## **Appendix 4**

### **Information about Participant Mothers**

A) *Demographic questionnaire*

B) *Table A.1: Information about Participant Mothers*



***Maternal Transitions: When Children with Autism Start Primary School***

**Participant Information Sheet**

Mother's name: \_\_\_\_\_

Mother's year of birth: \_\_\_\_\_

Father's year of birth: \_\_\_\_\_

Child's name: \_\_\_\_\_

Child's date of birth: \_\_\_\_\_

Child's diagnosis: \_\_\_\_\_

Number of children and other dependents in your family:

\_\_\_\_\_

Age of children and dependents: \_\_\_\_\_

**Education**

What is the highest grade you completed in school or further education?

\_\_\_\_\_

What is the highest grade your child's father completed in school or further education?

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What types of schools did you attend?

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What types of schools did your child's father attend?

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Child's current school setting (e.g. mainstream, support class, special school) and sector (government, Catholic or Independent)

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## **Financial Resources**

Which of the following best describes your family's current living situation?

- ☐ Currently we have no permanent home
- ☐ We live rent free in a house owned by relatives or friends
- ☐ We share a house/flat/unit, as joint tenants, with others and share the expenses
- ☐ We rent a house/flat/unit and are solely responsible for the payments
- ☐ We rent a Department of Housing house/flat/unit [or other social housing]
- ☐ We own a house/flat/unit and are making mortgage repayments each month
- ☐ We own our house/flat/unit free and clear

How is your family doing financially? (Please tick one)

- ☐ Not enough for basics, struggling each month to get through
- ☐ Meeting only basic needs each month, but enough for that
- ☐ Financially adequate, but little savings or investment possible
- ☐ In good financial condition

Please tick the box which best reflects your family's total annual income.

- ☐ 0 - \$9,999
- ☐ \$10,000 - \$19,999
- ☐ \$20,000 - \$29,999
- ☐ \$30,000 - \$49,999
- ☐ \$50,000 - \$74,999
- ☐ \$75,000 - \$100,000
- ☐ Over \$100,000

**Current contact details**

Home address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_



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Table A.1  
Information about Participant Mothers

Mother	Age in 2009	Number of children	Highest level of education	Housing situation	Financial description	Ethnicity	Marital status	Mother's occupation <sup>b</sup>
1	37	2	Postgraduate qualifications	House owner with mortgage	Financially adequate	Anglo-Australian	Married	Legal professional (part-time)
2	34	2	TAFE <sup>a</sup> (post-secondary study)	Renting a house	Good financial condition	Anglo-Australian	Married	Sales worker (part-time)
3	33	2	University degree	Renting a house	Financially adequate	Anglo-Australian	Single mother	Advanced clerical worker (part-time)
4	47	2	Year 12	House owner with mortgage	Meeting only basic needs	Anglo-Australian	Married	Elementary service worker (part time)
5	41	1	Year 10	Unit owner with mortgage	Meeting only basic needs	Vietnamese	Married	Food tradesperson (part-time)
6	31	2	University degree	House owner	Financially adequate	Italian-Australian	Married	Not working (previously a health professional)
7	33	3	University degree	Paying reduced rent in unit	Meeting only basic needs	Anglo-Australian	Married	Not working
8	39	2	University degree	Unit owner with mortgage	Financially adequate	White South African	Married	Business professional and sales worker (part-time)
9	41	2	Postgraduate qualifications	House owner with mortgage	Financially adequate	Anglo-Australian	Married	Musician (part-time)
10	38	2	TAFE (post-secondary study)	House owner with mortgage	Financially adequate	Anglo-Australian	Married	Intermediate clerical worker (part-time)
11	29	2	University degree	House owner with mortgage	Financially adequate	Anglo-Australian	Married	Not working (previously a health professional)
12	32	2	University degree	Unit owner with mortgage	Meeting only basic needs	Lebanese-Australian	Married	Not working
13	48	1	University degree	Renting a house	Financially adequate	Eastern European	Married	Social welfare professional (part-time)
14	30	2	University degree	House owner	Good financial condition	Italian-Australian	Married	Business and administration professional (part-time)
15	36	2	Year 11	Living rent free in parents' house	Financially adequate	Anglo-Australian	Married	Not working
16	38	1	University degree	House owner with mortgage	Good financial condition	Anglo-Australian	Married	Not working
17	48	2	University degree	Unit owner	Financially adequate	Anglo-Australian	Single mother	Education professional (part-time)
18	35	2	Postgraduate qualifications	House owner with mortgage	Financially adequate	Anglo-Australian	Married	Not working (doing further postgraduate study in education)
19	35	4	University degree	Living with in-laws	Financially adequate	Anglo-Australian	Married	Not working (previously a business manager)
20	40	3	University degree	House owner with mortgage	Good financial condition	Anglo-Australian	Married	Not working (previously an education professional)
21	38	2	TAFE (post-secondary study)	House owner	Financially adequate	Italian-Australian	Married	Not working
22	40	2	Postgraduate qualifications	House owner	Good financial condition	Anglo-Australian	Married	Not working (previously a health professional)

*Note.* All of the information is based on self-report.

<sup>a</sup> TAFE refers to Technical and Further Education. In Australia TAFE institutions provide a wide range of predominantly vocational tertiary education courses.

<sup>b</sup> Employment descriptions are based on the Australian Standard Classification of Occupations, Second Edition, [http://www.ausstats.abs.gov.au/ausstats/free.nsf/0/A86A0162E6F672DFCA256ADB001D10D4/\\$File/asco.pdf](http://www.ausstats.abs.gov.au/ausstats/free.nsf/0/A86A0162E6F672DFCA256ADB001D10D4/$File/asco.pdf) (accessed 31 March, 2014).

Table 8.1  
*Mother and Child Information for the 8 Reported Cases of School Change*

Mother	Age in 2009	Child	Total number of children	Highest level of education	Financial description	Ethnicity	Marital status	Mother's occupation <sup>b</sup>	Child's age in 2009	Child's diagnostic label	Child's education settings in chronological order, 2010-2012
1. Angela	34	Jarrold	2	TAFE <sup>a</sup> (post-secondary study)	Good financial condition	Anglo-Australian	Married	Sales worker (part-time)	4	High-functioning autism	Independent autism-specific special school; non-local government mainstream with support
2. Camilla	38	Christos	2	TAFE (post-secondary study)	Financially adequate	Italian-Australian	Married	Not working	5	Autistic Disorder; borderline	Non-local Catholic mainstream with support; Independent autism-specific special school
3. Gaby	47	Lance	2	Year 12	Meeting only basic needs	Anglo-Australian	Married	Elementary service worker (part time)	5	Aspergers Disorder	Independent multi-categorical disability support class; Independent autism-specific special school
4. Jana	32	Anthony	2	University degree	Meeting only basic needs	Lebanese-Australian	Married	Not working	5	ASD & global developmental delay	Home-schooling; Independent autism-specific special school; Independent autism-specific support class; Independent autism-specific special school
5. Lena	48	Guy	1	University degree	Financially adequate	Eastern European	Married	Social welfare professional (part-time)	6	Autistic Disorder & ID	Independent autism-specific special school; government support class for moderate ID
6. Melissa	37	Callum	2	Postgraduate qualifications	Financially adequate	Anglo-Australian	Married	Legal professional (part-time)	5	High-functioning autism	Local government mainstream with support; Independent autism-specific support class; Independent autism-specific special school
7. Natalie	29	Evan	2	University degree	Financially adequate	Anglo-Australian	Married	Not working (previously a health professional)	5	ASD; borderline	Local government mainstream with support; government autism-specific support class
8. Sally	40	Todd	3	University degree	Good financial condition	Anglo-Australian	Married	Not working (previously an education professional)	5	Mild autism; borderline	Independent mainstream with support; Independent special school

*Note:* All of the information, including child's diagnostic label, is based on maternal report.

<sup>a</sup> TAFE refers to Technical and Further Education. In Australia TAFE institutions provide a wide range of predominantly vocational tertiary education courses.

<sup>b</sup> Employment descriptions are based on the Australian Standard Classification of Occupations.

