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Crying in the park: Autism stigma, school entry and maternal subjectivity

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.[1]

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., 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').[2] 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 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

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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)[3] 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', 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 monstrously 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.

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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

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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

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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 (Hoschschild 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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[1] 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).

[2] 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).

[2] 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.

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