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“Everybody just freezes. Everybody is just embarrassed”: Felt and Enacted Stigma among
Parents of Children with High Functioning Autism

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Abstract

This paper reports the results of a study of felt and enacted stigma among a sample of parents of children with high functioning autism. The results indicate that a majority of the parents experienced both types of stigma, but that mothers were more likely to do so than fathers. This was especially true in the case of enacted stigma, where a majority of mothers, but only a minority of fathers, encountered avoidance, hostile staring and rude comments from others. The child's type of autistic symptoms was also related to the stigmatisation of their parents, with parents of aggressive children more likely to experience stigma than the parents of passive children. The study also found that the distinction between felt and enacted stigma was more distinct analytically than it was in practice, as many parents tended to conflate the different types of stigma. The results of the study are considered in the context of the changing conceptualisations of and treatments for high functioning autism and their implications for the stigmatisation of parents.

Introduction

High functioning autism or Asperger's syndrome¹ is a condition that often presents severe problems for parents, as they try to cope with the demands produced by their child's disability and the social consequences that flow from it. Individuals with this condition have normal range IQs, extensive verbal abilities and usually attend regular schools. Nevertheless, their disability is potentially serious. Their problems commonly include impaired social relations, obsessions, uneven levels of intellectual and cognitive functioning and peculiarities in language acquisition and functioning (Lincoln et al. 1988, Szatmari et al. 1989, Tantum 1991).

Despite these problems, people with high functioning autism must make their way in the social world without many of the protections available to those with more profoundly autistic symptoms. For example, they usually attend regular schools instead of schools for children with disabilities. Their disability is often not recognised, or, if it is, diagnosed years after its onset. Furthermore, they will eventually have to work, live independently and otherwise enact a typical adult role. In other words, they are people with a disability who must deal with the social world as if they were not disabled. The implications of this for problematic social interaction are considerable.

One of the problems they experience through social interaction is stigma. This is a problem that not only may affect the individual with high functioning autism, but has the potential to extend to their family as well. Indeed, research indicates that the parents of children with disabilities – including low functioning autism - commonly experience stigmatising reactions from others (Baxter 1984, Birenbaum 1970, Chesler and Barbarin 1984, Evans 1983, Gray 1993, Scambler and Hopkins 1986, Voysey 1975). Less is known, however, about the case of stigma and high functioning autism. The purpose of this paper is to

address this issue and examine the stigma experienced by the parents of children with high functioning autism.

Review of the Literature

Stigma, as a sociological concept, was developed by Goffman (1963) and has been applied to a wide range of adult illness experiences (Becker 1981, Bury 1988, Hopper 1981, Jacoby 1994, Lawless et al. 1996, MacDonald 1988, Nijhof 1995, Scambler and Hopkins 1986). Its use in the study of families of children with disabilities has been less common, however, there is a small body of research that has explored the effects of stigma in this context. (Baxter 1984, Birenbaum 1970, Gray 1993, Scambler and Hopkins 1986, Voysey 1975, West 1986). This research has focused on two main themes, the first of which is the nature of the stigma and the second is the way that parents have experienced and coped with it.

Researchers have generally agreed that the parents of children with disabilities experience what Goffman defined as a "courtesy stigma" (Baxter 1984, Birenbaum 1970, Gray 1993, Scambler and Hopkins 1986). This is a stigma of affiliation that applies to people who associate with stigmatised groups rather than through any quality of their own. In the case of families of children with disabilities, a courtesy stigma is attributed to their parents because they are members of the same family rather than due to any sharing of the disability itself. Goffman's (1963) original discussion of courtesy stigma emphasised a degree of choice exercised by those affected by it, as his examples included straight bar tenders in gay bars and the maids of expensive prostitutes. In these examples, the courtesy stigma is presumably a result of the supposed "moral" failings of these individuals because they choose to associate with stigmatised groups. Parents, however, are different. Their association with a child with a disability, and their consequent stigmatisation, is one that is encouraged by the social audience because of the parents' responsibilities as child raisers

and carers (Birenbaum 1970, Gray 1993, Voysey 1972). As a consequence, the parents of children with disabilities find themselves in a contradictory position. On the one hand, they are stigmatised by their relationship to their child, and, on the other, they would probably be condemned if they refused the association.

The second theme from the literature concerns the issue of how parents experience and cope with stigma. In his discussion of the possible responses to stigma, Goffman (1963) noted a distinction between stigma that are "discredited" and those that are "discreditable". The former refers to stigma that are visible and the latter to stigma that are not. Due to the associational nature of a courtesy stigma, the stigma experienced by the parents of children with disabilities would fall into the category of a discreditable stigma (Voysey 1972). This means that the coping strategy of the parents will primarily concern itself with the problem of information control concerning their child's disability. One option is to attempt to narrowly restrict information and engage in "passing" as a "normal" family. Indeed, passing is sometimes inevitable given the fact that children with disabilities are unlikely to accompany their parents on every public outing. Parents, however, are also likely to use the services of medical and educational personnel for their child's treatment and often will join self-help groups for the families of children with disabilities. This has the result of making their courtesy stigma more visible, invalidating the option of passing, and threatening what Birenbaum (1970) termed "a normal appearing round of family life". As a consequence, parents may avoid excessive involvement with organisations for the disabled and go through "cycles of affiliation" where their activities with such groups vary depending on their needs and circumstances (Birenbaum 1970).

Because parents do not usually have the option of passing in all circumstances, they have to confront the problem of limiting their exposure to the stigmatising reactions of others in different ways. The techniques for doing this include restricting public encounters (Voysey

1972), selective disclosure (West 1986) and restricting their socialising to friends who would show "consideration" for their child's condition (Birenbaum 1970). These techniques, either singularly or in some combination, provide parents of disabled children with some degree of protection against the stigmatising reactions of others.

Although previous research on this issue has provided valuable insights, there has been a tendency to over emphasise the situational context of a courtesy stigma, seeming to suggest that the stigmatisation of parents only occurs when they accompany their stigmatised child in public places (Birenbaum 1970). This focus on the situational context of a courtesy stigma over emphasises the significance of face to face interaction in the parents' experience and de-emphasises the broader biographical nature of their relationship with their child. To an extent this is understandable, as Goffman (1963) emphasised the interactional context of stigma in his own work. However, he also acknowledged broader identity related issues and how they are stabilised or challenged in the various aspects of the individual's social world. To put it somewhat differently, the core issue in regards to courtesy stigma is the success or failure of the individual in maintaining a "normal" identity. The process of achieving this, and the identity arising from it, are always precarious. The interactional context is where success or failure is actively achieved as the individual strives to deal with stigma by performing a "normal appearing round of life". However, stigma – in this case a courtesy stigma – is not limited to the interactional context. Rather it is stretched across social contexts to produce a more generalised, though situationally sensitive, biography of the individual. The significance of this for the present context is that a courtesy stigma for the parents of children with a disability is not limited to the social occasions where they are in their child's presence. Rather they can experience a courtesy stigma as a product of their larger biographical relationship with their child and their "known about" identity as the parent of a child with a disability.

It is in this context that the distinction between "felt" and "enacted" stigma is significant (Jacoby 1994, Scambler and Hopkins 1986). The concept of enacted stigma is relatively straightforward, and refers to instances of overt rejection or discrimination experienced by stigmatised individuals. In contrast, felt stigma refers to feelings of shame or the fear of rejection. This distinction is significant in terms of the relationship between the interactional and biographical aspects of stigma. As previously noted, the sustaining of a "normal" identity in the face of a potential courtesy stigma is inherently precarious. It is also an outcome that is achieved in an interactional context, but not limited to it due to the broader biographical nature of the relationship between the stigmatised individual and his or her associates. The distinction between enacted and felt stigma is relevant to these facts, because the experience of enacted stigma signals that the interactional context has broken down and that the individual with the courtesy stigma has failed to achieve a normal appearing round of life. The experience of felt stigma is also significant in that it refers to an individual's fear of failing to enact a normal appearing round of life and reflects the essential precariousness of maintaining a normal identity in the face of a possible failure of interaction.

The purpose of this paper is to examine the distinction between felt and enacted stigma in the context of the courtesy stigma experienced by parents with children who have high functioning autism. Little is known about the stigma experienced by the parents of such children, but there are reasons to assume that it may be substantial. As previously noted, individuals with high functioning autism are likely to have to engage in a series of typical social activities which exposes them to numerous opportunities to encounter the stigmatising reactions of others. In all of this, their parents will play a large role, as they are the ones who must guide the child in his or her encounters with individuals and organisations outside the family. As a consequence, they too may encounter the

stigmatising reactions of others. Accordingly, their experiences may be useful in examining the distinction between felt and enacted stigma among individuals with a courtesy stigma.

Methodology

The results reported here are taken from an ongoing study of the social experiences of families of children with autism based in the Brisbane metropolitan region of Australia. The participants included in the analysis for this paper were parents of children who have been diagnosed by the staff² at an autistic treatment centre as having high functioning autism or Asperger's syndrome. Forty families were asked to participate in the study and at least one member of thirty-three families agreed to be interviewed for an uptake rate of 82.5%. One family that originally agreed to participate was later excluded when a subsequent diagnosis of their child indicated that the initial diagnosis of high functioning autism had been incorrect. Among the remaining families who agreed to participate, thirty-two mothers and twenty-one fathers were interviewed for a total sample of fifty-three parents. The number of families where both parents were interviewed was twenty-one.

The children with high functioning autism from the families in this study included both minors and young adults. Their ages ranged from five to twenty-six with a median age of twelve. Slightly over two-thirds of the children were in the nine to fourteen age range. The symptoms of the children were equally varied, but all had age appropriate language skills and nearly all were attending a regular school or had done so in the past. Three of the families had more than one child with autism, and five had other children who had been diagnosed as having attention deficit hyperactivity disorder or a related behavioural problem.

The data for this study were collected through in-depth semi-structured interviews. The majority of the parents were interviewed in their homes, although a small minority preferred to be interviewed at the local autistic treatment centre, and one parent was interviewed at his office. The parents were interviewed separately except for one couple who preferred to be interviewed together. The issues that were covered in the interviews included the following broad categories: the onset of symptoms, referral experience and diagnosis, the nature of the child's present symptoms and the effects of autism on the family. The interviews were audio taped for subsequent analysis and varied in length from approximately one hour to over four hours in length. The typical interview lasted from two to three hours.

Stigma was one of the issues that were discussed in terms of the effects of autism on the family. As previously noted, this research has followed Scambler and Hopkins (1986) distinction between "felt" and "enacted" stigma. In an effort to distinguish between the two, the questions concerning stigma were more structured than many of the other questions in the interview. In particular, the parents were asked: "Do people treated you or your children differently because of your child's disability?" If they replied in the affirmative, subsequent questions were asked to ascertain whether their reply was based on the specific actions of others, or, alternatively, on the parents' assumptions about what others might be thinking. If the parents cited explicit acts of rejection, they were considered to have experienced enacted stigma. If, on the other hand, they could not point to behaviours, but, rather, referred to what they believed others were thinking, then they were considered to have experienced felt stigma.

The data were analysed through an interactive process commonly used in naturalistic research (Erlandson et al. 1993). First, each interview was indexed and selectively transcribed. This process followed the broad categories and order of the questions used in

the interview schedule. Second, the material was examined for identifiable themes in the parents' comments. As the interviewing progressed, the parents' responses were grouped into various categories of response on the basis of their emerging thematic similarity. Finally, once the interviewing was completed, the responses were analysed to examine the variations of felt and enacted stigma according to the different personal characteristics and situations of the parents.

Results

The Nature of the Experience: Felt and Enacted Stigma

The interviews revealed that a large majority of the parents did experience felt stigma, as slightly over three quarters of the parents claimed that they believed that others considered them to be different because of their child's autism. Most commonly parents imagined that others were critical of their child raising abilities, not accepting of them and made them feel embarrassed. The latter, embarrassment, was the most common manifestation of felt stigma among the parents in this study. As one mother commented:

As a mother, when a child sort of acts up... you don't want him to do it, because it's a bit embarrassing. And you feel like it reflects on you a little bit. I mean I'm intelligent enough to know that that's not the case, but it's very difficult to take yourself away from the situation. [05]

Felt stigma was most commonly experienced in public situations such as social outings and shopping. As Voysey (1972) noted, it is in such public situations where the parents' competence is most likely to be judged and where the presence of a disabled child threatens the ability of parents to affect a presentation of family normality. In such circumstances, the child's inappropriate behaviour can generate extreme feelings of embarrassment for the parents. As one mother related:

We went on a... camp and we were pretty apprehensive about going... We were the only ones with an autistic child and... he performed in front of all those people there and had to take charge. And he called me an idiot in front of all those people, and swearing started to come out, and everybody just freezes. Everybody is just embarrassed. [27]

One of the more problematic aspects of the distinction between felt and enacted stigma is that although they are analytically separate, the two types of stigma often merge in the experiences of the parents. For example, when the parents were questioned about their stigma experiences, they would often have difficulty distinguishing between the two and required clarifying questions in order for the interviewer to ascertain whether their perceived stigmatisation was based on others' behaviour or their assumptions about what they might be thinking. As this quote indicates, the experience of stigma is often based on a perceived combination of the two and may have the effect of overestimating the frequency of enacted stigma. In this case, it is uncertain what the parent meant by the behaviour of 'freezing', but it is certain that feelings of perceived embarrassment were projected onto the thoughts of the social audience. The difficulty that parents had in initially distinguishing between felt and enacted stigma is one of the more significant findings of this research.

Parents less commonly experienced unambiguously enacted stigma, as only about half had actually been the recipient of negative reactions by others. When they did occur, these reactions took three main forms, the most common of which was avoidance. Parents frequently noted that others didn't invite them over to their homes for social occasions such as dinners or parties, or, if they did often didn't invite them back. As one father said:

Occasionally we'd ask [some] family down and we'd have a drink or whatever, but we never got invited [back]... we never seem to be reciprocated. They don't say, "Well, come over". So, yes, you do feel like they've sort of judged and thought, "Give them a miss". [11]

Such reactions were often disturbing to the parents, especially when they affected the social lives of the other children in the family. However, the effects of avoidance were somewhat lessened by the fact that most parents had already restricted their social lives to accommodate the potentially disturbing encounters that could arise by their child's inappropriate public behaviour. In these cases, the families seldom had people over or went out to dinner or shopping as a group. Some compensated for this restriction by doing more activities such as picnics, hiking or trips to parks where the family might be less likely to interact with others and where inappropriate behaviours might be more easily tolerated. Others compensated by socialising with other families who had children with autism. This had the advantage of being with people who would understand if their child misbehaved. Nevertheless, the avoidance by others and the resulting limitations on the abilities of the families to socialise was often felt by the parents to be a considerable loss.

Another manifestation of enacted stigma was overtly hostile staring by others. This usually took place in the context of a public encounter where the child had behaved in a socially inappropriate manner. In these cases, the parents were already in a situation where they were embarrassed and the negative reactions of others were particularly hurtful. As one mother said:

I have always taken my boys shopping, always... Oh it's a disaster initially. [My son] threw a jar of vegemite at an elderly old lady who smiled at him, you know... they look at me as though I'm a mother who obviously isn't very good at being a mother. [14]

At least avoidance, and even staring to some degree, can be regarded as relatively non-provocative. Rude comments by others, however, are much harder to ignore and frequently prompted parents to react. Sometimes parents attempted to defuse the situation by explaining the nature of their child's disability to the person who made the comment. Often this was successful and the other person was mollified, and, sometimes, even apologetic.

Other times, however, an explanation made no difference. In these circumstances, parents sometimes reacted with considerable anger of their own. As one father related:

I never make excuses for him because... I want him to think he's normal. And if he mucks up, I don't just [say] to a group of people, " Oh, forgive me for the way he behaves. He's autistic. Please excuse him."... I only bring it up if people... start talking about him. I just happen to say to them, "He has high functioning autism". And... straight away I'll get a... sympathetic response... [However] I get people [who] will turn around and say, "Oh, there's nothing wrong with him... He just needs a good kick in the backside", you know. And I just end up saying, "You need a smack in the mouth". [49]

Distinctive Aspects of Stigma: Social Exposure and the Visibility of the Condition

Whether the nature of the stigma experienced is felt or enacted, it often has considerable effects on the parents of children with high functioning autism. In this regard, the parents' experience is similar to that of parents who have children with other types of disabilities (Birenbaum 1970, Scambler and Hopkins 1986, Voysey 1975). There are, however, at least two distinctive aspects to the experience of stigma in the case of high functioning autism, both of which are related to the relatively "mild" nature of the condition's symptoms.

First, despite being a potentially serious disability, high functioning autism does not necessarily prevent those with it from engaging in a wide range of regular social activities. Indeed, given the relatively high level of abilities among children with high functioning autism, parents are inclined to promote their child's involvement in social activities such as clubs and sports in order to help them improve their social skills. Furthermore, children with high functioning autism are usually enrolled at regular schools, although some may be located in special education classes within such schools.

One common effect of this relatively high level of social involvement is social rejection for both the children and their parents. Many of the children in this study experienced isolation

and/or bullying at school or in clubs, and relatively few had succeeded at establishing friendships with other children. For their part, the parents had the responsibility of dealing with the problems that arose from this rejection. Relations with teachers and school administrators were often cited as a problem for parents. However, their interactions with the parents of other students at their child's school were also difficult. A number of the parents cited their experiences at their child's school as situations where they were made to feel different because of their child's disability. As one mother said:

I suppose with the other parents at the school I feel a bit odd. With the parents of normal kiddies I feel, I don't know, like looked down on a bit, that sort of feeling... It bothers me. [44]

Another distinctive aspect of stigmatisation in the case of high functioning autism arises from the fact that the disability is not evident to outsiders. As such, it falls into Goffman's (1963) category of discreditable rather than discredited stigma. This is true even in the case of low functioning autism, although the markedly bizarre nature of its symptoms would often lead others to suspect a disability. In the case of high functioning autism, however, the nature of the disability is far less evident. As a consequence, when children with high functioning autism misbehave in public or act in a socially inappropriate manner, onlookers are more likely to react in a negative fashion. As one mother said:

I can walk through shopping centre after shopping centre and no one knows my child's autistic or he's got a problem. So, if he sees a drink machine and he wants a drink, and I haven't got the right change and he stands there... and screams, "I want a drink!", it runs through my mind, "What must some people be thinking?"... Do you say to them the reason he's carrying on like this is because he is autistic?... Actually, there were times when I thought, "God! I wish he were Down's syndrome", because people would leave me alone. They would see the Down's syndrome [and] know there was a problem. [45]

High functioning autism is not a disability that is obvious to the public. This does not mean, however, that it cannot be severe in terms of its effects on public encounters. In fact, its low visibility, along with the relatively extensive social involvement of these children and their

families, means that they may be exposed to more incidents of stigmatising reactions from others, without the obvious explanation of disablement that other conditions can call upon in public encounters. As such, high functioning autism has some relatively distinctive characteristics in terms of its stigmatising effects on parents.

Variations in Stigma: The Sex of the Parent

Although the majority of the parents experienced stigma, some parents were more likely to encounter it than others were. Despite the fact that a majority of both mothers and fathers experienced felt stigma, mothers were much more likely to do so than fathers. In the case of enacted stigma, only a minority of fathers reported that they had encountered it, while a majority of mothers had experienced avoidance, hostile staring and rude remarks from others.

There are several possible reasons for this difference between mothers and fathers. One is the fact that the mothers were more likely to be the parent who had to deal with public encounters. They were more likely to be the parent who took the child shopping, mediated in the problems that arose in the neighbourhood and were called to school when their child misbehaved. This was especially likely to be the case when they were not working outside the home. As one mother said:

I think that the big difference is the fact that I'm more free to involve myself in [my son's] education, so to speak. I can be available because I'm not working. I can get to school and I can talk to the teachers. And I can put out newsletters for them and that type of thing and [my husband] can't. [51]

Second, due to their traditional role as primary caregiver, mothers may feel and/or be attributed more responsibility than their husbands for their child's behaviour (Anderson and Elfert 1989, Voysey 1972). In particular, mothers are usually viewed as the parent with the

highest degree of responsibility for their child and they often feel considerable guilt for their child's disability (Anderson and Elfert 1989). Furthermore, they are in the position where they must demonstrate their parental competence, both to health care professionals and to the public at large in their daily interactions (Anderson and Elfert 1989, Voysey 1972). Consequently, mothers are much more likely to be the parents who experience the responsibility if that presentation fails. Several mothers in the present study reported that they were keenly aware of this aspect of their role, especially if they were not employed outside the home. As one mother said:

Especially if you are a full-time mum. If you are home with the children all the time, because you are having the major effect on your child's upbringing. Much more than your husband is... because that's the job you've got when your home full-time. That is your job and you're planning the children's day. You're responsible. [53]

However, even mothers who worked outside the home often believed that they were the parent who was considered the most responsible for their child and his or her problems. As one mother commented:

That's just the way it is. I don't know how you change that. Basically, roles haven't changed, have they? People have still got those opinions. Maybe the roles have changed, but the opinions haven't. [12]

Not surprisingly, the more frequent encounters with both felt and enacted stigma were distressing to the mothers who experienced them. They felt that it was an added burden to the already considerable problems they faced in dealing with their child's disability and its effect on their family. As a means of coping with this problem, mothers tried a variety of strategies to ameliorate the effects of stigma on their lives. Most simply ignored what they could. Others lessened their contact with people and situations where they were more likely to encounter bad reactions or tried to explain the nature of the problem to onlookers when bad reactions occurred. Still others, however, tried other approaches to dealing with the

problem, some not without a degree of humour. As one mother with a particularly disruptive child said:

I often smile at them and give them a wave and give them a wink, you know. And they don't know how to take that because they think that I might be loony too, you know. Because if I can smile and turn it into a joke, I say, "I'm very good at training horses, but at the moment I'm not too successful with children. But I'm working on it".... If I can make myself laugh at it, then it's fine. It doesn't get to me. [14]

Such creative responses, however, are difficult to maintain, especially in the face of frequent negative reactions by others. More often mothers were involved in too many public encounters to attempt anything more than the previously noted reactions to other's responses such as avoidance and explanation.

Variations in Stigma: The Symptoms of the Child

The nature of the child's autistic symptoms also had an effect on the stigma experience of their parents. In particular, the parents of children who were aggressive or violent were far more likely to experience enacted stigma than parents with more passive children. The reasons for this are not hard to understand, as aggressive children are more likely to disturb others, and, consequently, provoke a greater reaction. One mother described a previous experience:

We went for a walk [and a] bike rider was going through... and [my son] got this plastic bag and just threw it at this lady. And he was standing right here in front of her. Oh, and she said, "How dare you do that. Can't you keep control of your kids". [47]

The problem of aggression is particularly difficult in school, where some of the children in the study experienced frequent conflicts with teachers or fellow students without a disability. In several cases, these problems had resulted in violent outbursts and led to suspensions and expulsions. For their part, the parents are the ones who are placed in the

role of mediators between their children and educational administrators who have a responsibility to maintain order and protect the safety of other students. As a consequence, the parents often have bad experiences with school authorities. As one mother said:

I've had a gut full. Just... school last week. I thought, "I've had a gut full of this. Why am I bothering? Why am I pushing him through school? Why don't I take him out? Give him distance education". I'm sick of the hassles with school. [51]

This is often a source of considerable distress for the parents of aggressive children. As the previously quoted mother said:

There are days when I fall apart. Towards the end of last year at school, I've left school in tears... I mean, that sort of thing happens quite often and you try to shut it out and distance yourself from it. [51]

Despite the problems aggressive children experience in school, few parents take the option of removing them. Part of the reason for this is that there are not many other options available, as many parents have to work and leaving the child at home unattended is not possible. However, most parents also believe that their children must learn to cope with their aggression if they are ever going to lead successful independent lives, and school is the obvious place for them to learn appropriate social behaviour. As a consequence, they prefer to continue dealing with school problems as they arise and accepting the stigmatising repercussions of their child's behaviour for their own identities as parents.

Conclusion

Since it was first clinically described in the 1940s, medical thinking about what are now termed autistic spectrum disorders has changed considerably. In particular, previously they were thought to be extremely rare, caused by a failure of bonding between the parent and child and treatable by psychodynamic therapies such as psychoanalysis. High functioning autism (or Asperger's syndrome) was thought to be a less severe form of autism and

individuals affected by the condition were thought to be relatively fortunate in comparison with those who were more profoundly autistic.

The assumptions of contemporary medical thinking about autism are different in a number of ways. Now it is generally assumed that autistic spectrum disorders are relatively common, have a genetic basis and are best treated by a combination of behavioural training and drug therapy. In addition, individuals with high functioning autism, although perhaps less severely affected than those with profound autism, are nevertheless still recognised as having a potentially serious and in some ways unique developmental disability. Other changes have also eventuated. In particular, there has been a decline in the use of segregated specialised treatment centres for people with high functioning autism in favour of the mainstreaming of such individuals into regular schools.

Whether or not these developments are generally desirable is not within the scope of this paper. Rather, the issue here is stigma and how these developments might have affected the experiences of individuals with high functioning autism and their parents. It is possible that the aforementioned changes might have lessened the impact of stigma. For example, the growing recognition of the genetic basis for autism may have contributed to a decline of stigma experienced by parents of children with autism, as the responsibility for their child's disorder was shifted away from their actions and toward factors that were not under their control. It is also possible that the increasing public recognition of high functioning autism has reduced the stigma attached to such conditions. In particular, educational mainstreaming has increased the frequency of contact between children with high functioning autism and others, and, presumably, made it more familiar, less threatening, and reduced the stigma experienced by the individuals affected by it. Unfortunately, in the absence of longitudinal data, such conclusions can only be speculative.

What is clear from the results of this study is that individuals with high functioning autism and their parents still experience considerable stigma. Furthermore, it is possible that some of the contemporary ways of treating autism may have had no significant effect on stigma or may have actually contributed to its impact. To begin with, it is doubtful that the

assumption of a genetic etiology for high functioning autism has necessarily reduced the degree of stigma experienced by the parents of children with the condition. Indeed, sociological literature is replete with examples of various illnesses and disabilities that have a clear biological basis, but, nonetheless, result in significant stigma for the individuals affected by them. Certainly, the experiences of the parents in this study indicate that the presence of a medical diagnosis in itself did not seem to generally offset the stigmatising effects produced by their children's behaviour. Furthermore, it is uncertain that mainstreaming children into regular schools will necessarily result in a reduction in stigma. Although mainstreaming avoids the stigmatising effects associated with attending a special school for people with disabilities, which was the most common educational experience for such children in the past, it also increases their social contact with non-disabled children and the possibility for rejection by them. As the results of this study indicate, it also means that parents, especially mothers, may experience increased conflict with educational authorities because of their child's problems at school. In short, although there have been significant changes in medical thinking about high functioning autism and policies related to its treatment, it still remains a developmental disability that is highly stigmatising for those affected by it.

A final issue raised by this study concerns a methodological problem in relation to the study of stigma. In particular, the results of the study suggest that the conceptual distinction between felt and enacted stigma needs to be reconsidered. Scambler and Hopkins' (1986) introduction of this distinction was a useful attempt to provide a more sensitive analysis of the experience of stigma. It not only had the intuitive appeal of the "common sense" division between thought and action, but its utility was also established in their empirical analysis of study of stigma and epilepsy.

In the context of the present research, the distinction between felt and enacted stigma was similarly useful in that the two types of stigma did show different patterns of experience on the bases of the parent's gender and the child's symptoms. However, most parents in this study had trouble distinguishing between the two without being prompted by the interviewer. This indicates that the two types of stigma are more distinct conceptually than they are in the parents' experiences of them. In other words, most parents conflated felt and enacted stigma and experienced them as varying manifestations of the same negative experience. This suggests that while it may be useful to use this distinction in future studies of stigma, it is also necessary to be aware of the conceptual and methodological problems inherent in doing so.

References

- Anderson, J.M. and Elfert, H. (1989) Managing chronic illness in the family: women as caretakers, *Journal of Advanced Nursing*, 14, 735-743.
- Baxter, C. (1989) Investigating stigma as stress in social interactions of parents, *Journal of Mental Deficiency Research*, 33, 455-466.
- Becker, G. (1981) Coping with stigma: lifelong adaptation of deaf people, *Social Science & Medicine*, 15B, 1, 21-24.
- Birenbaum, A. (1970) On managing a courtesy stigma, *Journal of Health and Social Behavior*, 11, 3, 196-206.
- Bury, M. (1988) Meanings at risk: the experience of arthritis. In Anderson, R. and Bury, M. (eds) *Living with Chronic Illness*. London: Unwin Hyman.
- Chesler, M.A. and Barbarin, O.A. (1984) Difficulties of providing help in a crisis: relationships between parents of children with cancer and friends, *Journal of Social Issues*, 40, 4, 113-134.
- Erlandson, D.A., Harris, E.L., Skipper, B.L. & Allen, S.D. (1993). *Doing naturalistic inquiry: A guide to methods*. Newbury Park, California: Sage.
- Evans, D.P. (1983) *The Lives of Mentally Retarded People*. Boulder, Colorado: Westview Press.

Gray, D.E. (1993) Perceptions of stigma: the parents of autistic children. *Sociology of Health & Illness*, 15, 1, 102-120

Goffman, E. (1963) *Stigma*. Englewood Cliffs, New Jersey: Prentice-Hall.

Gray, D.E. (1993) Perceptions of stigma: the parents of autistic children. *Sociology of Health & Illness*, 15, 1, 102-120.

Hopper, S. (1981) Diabetes as a stigmatizing condition: the case of low income clinic patients in the United States. *Social Science & Medicine*, 15B, 11-19.

Jacoby, A. (1994) Felt versus enacted stigma: a concept revisited. *Social Science & Medicine*, 38, 269-274.

Lawless, S., Kippax, S. and Crawford, J. (1996) Dirty, diseased and undeserving: the positioning of HIV positive women, *Social Science & Medicine*, 43, 9, 1371-1377.

Lincoln A.J., Courchesne E., Kilman B.A., Elmasian R. and Allen M. (1988) A study of intellectual abilities in high functioning people with autism, *Journal of Autism and Development Disorders*, 18, 505-524.

MacDonald, L. (1988) The experience of stigma: living with rectal cancer. In Anderson, R. and Bury, M. (eds) *Living with Chronic Illness*. London: Unwin Hyman.

Nijhof, G. (1995) Parkinson's disease as a problem of shame in public appearances, *Sociology of Health & Illness*, 17, 2, 193-205.

- Scambler, G. and Hopkins, A. (1986) Being epileptic: coming to terms with stigma, *Sociology of Health & Illness*, 8, 1, 26-43.
- Szatmari P., Bartolucci G., Bremmer R., Bond S. and Rich S. (1989) A follow-up study of high functioning autistic children, *Journal of Autism and Development Disorders*, 19, 213-225.
- Tantum, D. (1991) Asperger syndrome in adulthood. In Frith, U. (ed) *Autism and Asperger Syndrome*. Cambridge: Cambridge University Press.
- Voysey, M. (1972) Impression management by parents with disabled children, *Journal of Health and Social Behavior*, 13, March, 80-89.
- Voysey, M. (1975) *A Constant Burden*. London and Boston: Routledge & Kegan Paul.
- West, P. (1986) The social meaning of epilepsy: stigma as a potential explanation for psychopathology in children. In Whitman, S. and Hermann, B.P. (eds) *Psychopathology in Epilepsy*. New York: Oxford University Press.

Footnotes

1. There is considerable debate over the issue of whether or not high functioning autism and Asperger's syndrome are different labels for the same disorder or represent separate disorders with highly similar symptoms. In the research reported here, they are treated as one disorder. The main reason for doing this is because the autistic treatment centre where the research was conducted did not distinguish between the high functioning autism and Asperger's syndrome in their diagnosis or treatment of the disorder.

2. Although the majority of the children in this study were diagnosed at the autistic centre, not all were. At the time of the research, the centre had recently started accepting children diagnosed as autistic by a limited number of medical practitioners and other qualified professionals in whose diagnostic abilities they had confidence. The purpose of this change in policy was to cope with an increasingly large number of clients.