Ten years on: a longitudinal study of families of children with autism

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This paper reports the results of a longitudinal, ethnographic study of the psychosocial adaptation of parents of children with autism. The results indicate that most parents have experienced improvements in terms of their own psychological well-being, the social experiences of their immediate family members and their relations with members of their extended family. They also reported changes to the stressful situations they experience and their strategies for coping with them. Stigmatizing reactions of non-family members have also declined. The results were less favorable in the cases of families with aggressive and/or violent children. The parents in these families experienced high levels of stress and had few resources in terms of treatment or residential placement to deal with their situation.

Longitudinal research on the social experiences of the families of children with autism is relatively rare; a fact that is surprising given the difficulties that autism presents to the development of family life. The studies that have been done are cross-sectional in nature, examining the effects on the family at specific points in time rather than tracing the development of problems and adaptations over a substantial period (Bristol, 1984, 1987; DeMeyer, 1979; Gray, 1994, 1998; Marcus, 1977; Marcus, Kunce & Schopler, 1997; Mesibov & Handlan, 1997). Nevertheless, taken as a composite, this literature presents a coherent perspective on the problem and indicates that such families experience a series of stages in their adaptation to their child’s autism.

In the child’s early years, after the onset of autism, parents experience an intensely stressful period as their child’s problems grow more pronounced and they struggle to obtain an accurate diagnosis and treatment for their child. This period ends with the diagnosis and placement of their child in appropriate treatment and educational programs (DeMeyer, 1977; Marcus et al., 1997). Over the next few years, although problems with schools, treatment providers and their other children are common, most families experience a relatively good period. In particular, improvements in the child’s sociability, emotional control and attention span mean that their behavior becomes more orderly and their family’s life more settled (DeMeyer, 1977).

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This period typically ends with the onset of adolescence, as the child’s problems often worsen. In particular, increasing physical and sexual maturity, increased frequency of seizures and parental emotional exhaustion are common problems during adolescence (Marcus et al., 1997).

Adulthood for the individual with autism presents additional problems for their families such as the need to find their adult child supervised living and working arrangements (Marcus et al., 1997). Although in the past it was common to institutionalize the majority of adults with autism (DeMeyer, 1977), this option is presently declining as de-institutionalization and community based programs are becoming the preferred means of providing long-term care (Marcus et al., 1997).

This pattern of family adaptation to autism describes a difficult process for parents. On the positive side, it involves the surmounting of early crises and the gradual adaptation of the family to the experience of living with a child with autism. On the negative side, it reflects the tenacity of the disability and its long-term effects on the family. There is, however, much that we do not know about this process. In particular, the absence of true longitudinal studies means that issues such as coping, social rejection, and how they change over time are not well understood. The purpose of this paper is to examine these issues by presenting the results of longitudinal research on the social experiences of families of children with autism.

Method

The results reported in this paper are from an ethnographic, longitudinal study of a cohort of families who participated in research that began a decade previously. The focus was not restricted to the child’s development, but rather emphasized the experiences of the parents and other family members as they coped with the changing problems of a developing child with autism.

Sample

In the original study, 35 parents (25 mothers and 10 fathers representing 26 families) of children under treatment at an autistic center were drawn from a larger quantitative survey study of the psychosocial well-being of families of children with autism conducted in New South Wales and Queensland. The number of participants in this survey was 172, from which a subsample of 77 parents living in Queensland were asked to participate in the qualitative phase of the research. Approximately 50 parents agreed to be interviewed; however, time and resources limited the subsample to 35 parents living in Brisbane and its adjacent coastal regions. The number of children in the original study was 24 and included 16 males and 8 females. All of the families had other children, although in two cases they were half-siblings from a previous marriage.

The children with autism in this study had been diagnosed at an autistic treatment centre where the primary diagnostic criteria were based on the DSM III R. Their autistic symptoms ranged from mild to severe with the majority experiencing moderate to severe degrees of impairment. Their ages ranged from 4 to 19, with approximately three-quarters of the children between the ages of 6 and 12. Although it would have been desirable to use a sample with a less varied age range, there was little choice, as the research was unavoidably restricted to using a group under treatment at the participating autistic centre. As a consequence, an additional restriction to a less age varied group, such as children in primary school years, would have significantly reduced the size of the sample. Nevertheless, it is
important to allow for the possibility that the different cohort experiences of the children might have some unknown effect on the results of the study.

In terms of service provision, at the time of the initial study, two of the children had at least part time residential placements in facilities for people with disabilities with one awaiting a full time placement. Another child who had recently been assessed at the center was awaiting an opening at the center for their daily non-residential program. All of the remaining children were receiving non-residential services from the autistic treatment center except one child who had a placement in a state special school for children with disabilities.

The present study was conducted approximately 8 to 10 years after the original one. Of the 35 original participants, 31 parents from the previous study were asked to participate and 28 (19 mothers and 9 fathers representing 20 families) agreed to do so. Those parents excluded from the longitudinal study had either moved out of the district or had been interviewed by another researcher and were considered to be inappropriate for purposes of comparison. These families included 20 individuals with autism (13 males and 7 females) whose ages ranged from 13 to 27.

The present situation in regards to services for the individuals with autism in this study was considerably different to that found in the previous research. In particular, none of them were still clients at the autistic center, although one family still attended an annual retreat that the center provided for families with children with autism. This declining role of the autistic center was partly due to the center’s changing nature of service provision which had shifted its emphasis to providing short-term care and acting as a referral service for other providers. However, the increasing age of the individuals with autism and their changing needs also contributed to this outcome, as half of them were 18 or over at the time of the follow-up study and few required the same type of life skills training that they had previously received at the autistic center. Instead, at the time of the follow-up study, 8 were attending a special school for children with disabilities, 8 were receiving some type of community service support, 2 were in residential care and 2 were receiving no services at all.

**Instrument**

In the first study, parents were interviewed about a number of issues related to their family’s experience of raising a child with autism. The length of the interviews ranged from approximately 1 hour to over 4 hours and included questions about the following: (a) the child’s medical history and referral experience, (b) the child’s present symptomatology, (c) the effects of the situation on the parent’s health and career, (d) the various effects of autism on the family’s social life, (e) parental coping techniques, (f) illness conceptualizations, and (g) parents’ expectations for their child’s future development. For purposes of comparison, most of the issues that were discussed in the follow-up study duplicated those from the previous research. Where appropriate, the questions were modified to make them relevant to the present situation.

**Results**

**Parents’ and sibling’s health and well-being**

The results from the previous research indicated a high level of emotional distress for many of the parents including depression, anxiety and anger (Gray, 1994; Gray & Holden, 1992). Less frequently, parents reported physical health problems, some of which may have had
a stress related component. Career problems were also common with some parents reporting moderate to serious limitations on their careers, and others, particularly mothers, denied any opportunity for outside employment due to their child’s disability.

Both parents were affected by these difficulties; however, mothers were especially likely to report severe distress. Although the small number of fathers in the study requires caution in interpreting these results, the degree of difference between the mothers and fathers was striking. There were several possible reasons for the mothers’ greater distress including greater involvement in child raising, increased exposure to negative social reactions by outsiders and the absence of employment and an alternative role to being the parent of a child with autism. It is impossible to know which, if any, of the reasons were the most important, but clearly mothers reported more distress than fathers in the previous research (Gray, 1994; Gray & Holden, 1992).

The present research found substantial amounts of self-reported psychological distress among the parents. However, the level of emotional distress was notably less than in the previous study and with less variation according to the sex of the parent. Improvement was particularly noticeable in cases where previously difficult children had matured into less disorderly teenagers and adults. As one mother said:

I think she’s a lot easier to live with … She went through so many stages of things … and she was unhappy. And if she’s unhappy that makes us all unhappy, but she’s happier [now] and that makes it a lot easier.

In many cases, however, their child’s disability still caused considerable upset among the parents. In particular, slightly over half of the parents reported significant degrees of anxiety and depression and approximately a third of these were receiving psychotherapy and/or medication to help them cope. Not surprisingly, the parents who were the most distressed were those whose children were aggressive and/or severely obsessive. In these cases, parents were often exposed to severely stressful circumstances, a situation that has worsened as their children have become larger and less easy to control. As one mother related:

Her behavior has gotten worse. Her anger has certainly gotten worse … It really is horrid living with someone who you’re never sure when she is going to turn on you and attack you. You can’t even enjoy a cuddle without being aware that at any second, for no reason at all, that cuddle might turn into a bite, a pinch or a scratch.

Career problems continued to be a difficulty for a number of parents, especially the mothers, as approximately half reported that their child’s autism prevented them from either working at all or restricted their hours and/or type of employment. Nevertheless, a few mothers who were previously not in the paid workforce had returned to work or were pursuing additional educational qualifications. Fathers were affected less in career terms, as all of them were employed and the work related problems caused by their child’s autism were relatively minor when compared with those experienced by their wives.

More positively, the parents generally reported a decline in the problems experienced by their other children. At the time of the initial research, a large majority of parents expressed significant concerns for the well-being of their other children and commonly cited the loss of typical family socializing experiences as one of the worst effects of autism on their families (Gray, 1994). This was still a concern. However, parents seemed less worried about this now than previously as only about a fifth of the families reported significant problems for their other children that were caused by their sibling’s autism. One reason for this was
that their other children were now usually adults or teenagers and had established stronger networks of relationships outside of the family. As one father who had previously been very concerned with this problem commented:

My son is going on 14 now and he’s got a lot of mates and his social life isn’t affected by [his sister] at all, I don’t think. Basically his mates know that that’s the way she is and they cautiously avoid her, but she basically retreats from them anyway. We’ve had no incidents at all and they’re nearly over here all the time. They come over and swim and party and do whatever they want to do … I think he’s got a very good teenager’s life at this point in time. Not a care in the world.

Parents also reported improved relationships with their extended families, and, especially, the child’s grandparents. This was in marked contrast to the findings of the previous research with this sample that found that many grandparents were highly critical of the parents’ child raising skills and frequently denied that their grandchild had a disability (Gray, 1998). In the follow-up study, most parents reported improved relationships with the child’s grandparents, as the reality of the child’s disability was confirmed over time and the grandparents grew more accepting of the situation. In other cases, differences between parents and grandparents were not resolved, but rather became less important due to a variety of factors such as the growing confidence of the parents in their child’s diagnosis and their own parenting abilities. Only two families noted significant continuing problems with their child’s grandparents and even in these cases the problems were not severe.

The families’ social experiences

The previous study examined a number of aspects of the families’ social experiences. Included among these were the issues of coping and stigma. In the previous study, parents were asked to describe the most difficult problems they experienced and how they coped with them. Among the most difficult problems that parents mentioned were poor language skills, inappropriate and embarrassing public behavior, disruption and destruction in the home, violence and aggression, inappropriate sexual expression and obsessions with eating or toileting (Gray, 1994).

Many of these problems have persisted over time. However, there was a shift in the significance of these problems from the parents’ point of view. In particular, communication was less frequently cited as a major coping problem, as only three parents considered this to be the most difficult aspect of their child’s autism. In some cases this change may have been due to improvements in their child’s abilities or increases in the parents’ capacity for understanding their child’s attempts to communicate. However, it may have also been due to a decline in parents’ expectations about communication and the development of more successful ways of dealing with their child’s limited communicative abilities. In any case, it did not appear to be as significant a problem as it had been earlier. There were also declines in the importance of poor public behavior, obsessions and toileting as coping problems.

There were, however, two problems that had increased in their significance for parents. One of these was anxiety about their child’s future. At the time of the previous research, a number of parents still had high hopes that their child would develop enough skills to live a “near normal life” as defined by semi-independent living and supervised work of a low skilled nature (Gray, 1993a). These hopes have declined, as none of the children have attained the full range of living skills that their parents originally envisioned. In fact, only
of the parents still had a modest degree of hope that their child would live a “near normal life” and even these hopes were heavily qualified. For example, one single mother, who had had high hopes for her son’s improvement a decade earlier, now was increasingly concerned about her son’s future as well as her own.

I want him to have some sort of employment, you know. Whether it means a sheltered workshop, whether that means there will be one for him to go into, I don’t know. But yeah, it’s a worry. If I can’t work I don’t know how I am going to support us. I can’t leave him home by himself obviously and I can’t leave him with my parents. I mean, they’re too old … But if I can’t get him employment … well, I’ll have to stay home. I don’t know. It’s no good. Everything depends on his arrangements.

The failure of children to recover, plus their increasing age, has meant that such issues as their future residential location and supervision have assumed more importance in the concerns of their parents. As previously noted, researchers have generally assumed that most children with autism would eventually be institutionalized, probably in a state facility for people with disabilities (DeMeyer, 1979; Gray, 1993a). However, in many places government policies have changed over the years, and the state of Queensland is no exception, as the option for institutionalization in a state facility has been severely restricted. As one angry parent commented:

There’s not enough there to help these people. And it’s not getting better, it’s getting worse. [Parents] could put these kids in institutions once. What is there now? There’s not much out there … People say to me, “Ah, but couldn’t you send [your son] somewhere?” It’s just like waving a red flag to a bull when they say that to me.

This has left parents with the problem of finding an appropriate residential placement for their child when they are no longer able to provide the home and supervision that they do at present. However, success in finding such accommodation is by no means assured, and, therefore, it is not surprising that anxiety about the future has become a more serious problem for the parents.

Another important coping problem is violence. This was noted as a significant problem in the earlier research (Gray, 1994). However, the increasing size of the children, and the consequently increasing vulnerability of the parents and siblings, have made this problem more serious as the children have aged. Somewhat surprisingly, several children who were violent and aggressive when younger have become more placid, while previously non-aggressive children have become violent when they reached adolescence. Approximately a quarter of the children were described by their parents as aggressive, and, in these cases, their families’ quality of life had been severely reduced. As one father commented:

You can’t exaggerate [the impact]. Friends of [my wife] just burst into tears at times … when she just starts doing something or attacks [my wife]. It’s just horrifying. It’s like a very nasty accident, an assault. If someone assaults you, it traumatizes you. If someone assaults you every day, I’m not sure what it does to you. But we get attacked, one way or another, every day.

The parents of these children are exposed to severely stressful circumstances, and, understandably, they were highly critical of the services that are available for families in their situation. Among the families participating in this research, they appeared to be the ones at greatest risk.
In terms of coping strategies, the previous research found that parents used a variety of ways to cope with the stress brought about by their child’s autism. Most popular were the use of treatment services and support from members of their family. Other coping strategies included religion, social withdrawal and various forms individual attainment and activity.

The present study indicates that there have been significant changes in the parents’ coping strategies. Most notably, the use of treatment services has declined dramatically. This is not surprising, as none of the children are now enrolled at an autistic treatment facility and many have finished their years in the state schools for children with disabilities. However, the absence of services appropriate for adolescents and adults with autism may also be a factor. A number of parents who had previously relied heavily on service providers, but were now less likely to do so, emphasized the absence of needed services for adolescents and adults. As one parent commented.

It’s very bleak at the moment. There’s nothing out there for these children, so it’s virtually up to the parents to provide for them. We could cope with [my son] if we had somewhere he could go during the daytime, right? To have an 18-year-old at home who has gone to school from the time he was probably 2 years of age … all of a sudden at home. He’s going to go around the twist … If they had centers that catered for what they needed, look, the parents would pay. I’m sure of it. I would … because that’s better than having an unmanageable child at home that’s making your life worse.

Social rejection or stigma was another issue that was examined in the previous research (Gray, 1993b). The results indicated that the parents experienced severe socializing problems and frequent social rejection. This was most commonly noted among the mothers, but extended to all members of the family. The follow-up research found that the majority of parents still experienced stigma and that mothers were again more likely to experience this than fathers. However, the impact of stigmatization may have declined over the years, as a number of parents noted its continuing occurrence, but claimed that it now mattered less to them.

The reasons for this are various including improved public behavior by the child and deliberate restrictions in the families’ social lives. However, in many cases, parents seemed to have become less sensitive to the reactions of outsiders and find stigmatizing behaviors less threatening to their self-esteem. Although several parents claimed that social rejection still disturbed them when it occurred, it did not seem to have the emotional impact on them that it did previously. As one mother said:

Most people are very good. They can see at a glance that he’s handicapped and they make allowances. But when he was younger, people were terrible … It’d be zero point one percent of people who are no good now. And [when something happens] I just sort of stand there and glare at them and I just say, “Well, he’s autistic, what do you expect?” [And they say] “Oh, sorry, sorry, sorry.” I’ve had to learn to be a little bit dominant too, you know, which I’m naturally not. But I’ve had to sort of pretend I am, sort of act it, yeah. And then people leave you alone.

More positively, several parents also noted their success in finding friends who accepted their child’s disability and helped them feel like they led more normal social lives. All of these factors may have combined to produce less reaction to stigmatizing behaviors than in the past.
Discussion

At least two conclusions may be drawn from the present research. The first of these is that the outcomes for most families in the study have been relatively favorable. Roughly two-thirds of the parents in the study claimed that their situation was better than it had been a decade previously. A variety of factors may have contributed to these improvements including the increasing manageability of the individuals with autism, accessibility to a mix of appropriate services, and, possibly, the increased coping abilities of the parents. Most studies of chronic illness in families show that successful coping is usually a long-term process where the affected family members gradually accumulate skills and develop perspectives on their situation that helps them to manage the problem (Berry & Hardman, 1998). Although there was no way to directly examine this in the context of the present study, the parents’ comments make it seem likely that such a process may have been operating.

The second conclusion is more negative. Not all families have experienced an improvement in their situations and recent changes in service provision may have made their problems worse. As previously noted, families with violent children are under tremendous levels of stress. These families perceived their level of service provision as very unsatisfactory and often believed that they may eventually need to find a placement for their child in a residential facility. Unfortunately, changes in the services provided by the state government and the cost of purchasing private services may make the possibility of residential care unlikely for all but the wealthiest of the families.

The lack of residential care is not a problem limited to families with violent children. Despite the fact that all but three of the individuals with autism in the present study were still living at home, there remained the problem of where they will live when their parents become too old to continue caring for them on a daily basis. Given the fact that few parents want their other children to take up the task of providing a home and daily care for a sibling with autism, the problem of finding residential care for their child is one that has been deferred rather than removed for most of the parents in this study.

References


