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PARENTS' EXPERIENCE OF HAVING A CHILD WITH AUTISM AND LEARNING DISABILITIES LIVING IN A GROUP HOME

A case study

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ABSTRACT

Some children with autism and learning disabilities also have aberrant behaviours difficult to regulate, stressful both for the child and for family members. The present case study concerns experiences of 10 parents from five families before and two years after entrusting their 10- 11 year old child with autism to a group home. Hermeneutic phenomenological analysis of narrative interviews with the parents before the child's moving showed them experiencing grief and sorrow, total exhaustion because of inability to regulate their child's behaviours, social isolation, and negative effects on the child's siblings, but experiencing themselves as more sympathetic than earlier towards other people with problems. Two years later they experienced relief for the family due to the group home arrangement and the child's improvement, but with an ethical dilemma, which made them feel guilty, despite increased hope for the future. Some also felt unhappy with the staff situation at the group home.

(150 words)

KEYWORDS

parents

exhausted

autism

group home

relief

INTRODUCTION

Up to the 1970s there were large institutions, called special hospitals, in Sweden for children with disabilities of various kinds. Since then, ideologies regarding children have changed, the general view now being that children with disabilities should not be separated from their parents (Grunewald, 2000). Today most children with autism live with their families. At the same time, since autism is a lifelong developmental disability with serious impairments involving social interaction, the ability to communicate, and patterns of behaviour, the presence of a child with autism seriously affects the family system as a whole (Sivberg, 2002a; 2002b). Numerous studies have shown that parenting a child with autism can produce stress in the family system (McKinney & Peterson, 1987; Dunn et al., 2001). Koegel et al. (1992) found the mothers, in particular, showed a high level of stress, describing them as having a consistent high stress profile associated with rearing the child. This conclusion was based on a study involving 50 mothers from varying cultural and geographic environments whose children varied both in age and functional levels. Sivberg (2002b) found a significant gender difference in a study of the coping strategies of 66 parents of children with autism, the mothers showing a lower sense of coherence than the fathers. In a study by Hasting and Brown (2002), 26 mothers and 20 fathers of children with autism reported on their self-efficacy, anxiety and depression. Teachers rated the behaviour problems of the children. Regression analyses indicated that the level of self-efficacy mediated the effect of the child's behavioural problems on the levels of anxiety and depression shown by the mothers but not on that of the fathers. Dumas et al. (1991) compared the level of parenting stress and of depression in parents having children with autism, with Down's syndrome, with behavioural disorders, or having typical development. They found that parents of children with autism and of children with behavioural disorders showed the highest levels of stress, and that

mothers of children with autism and of those with behavioural disorders experienced higher levels of depression than mothers of the two other groups. Olsson and Hwang (2001) assessed parental depression in 216 families with children with autism and /or learning disability and in 214 control families. Mothers of children with autism showed the highest depression scores. According to Sharpley et al. (1997), the three most stressful factors experienced by parents having a child with autism are concern regarding the permanency of the condition, the poor acceptance of autistic behaviours by society and often by other family members, and the failure of the parents to receive sufficient social support. Sanders and Morgan (1997) demonstrated that a lack of social support can result in parents withdrawing from the larger community because of the negative characteristics they associate with the disability of their child, which in turn increases their level of stress.

What causes the stress and depression in parents of children with autism? Do all these parents, especially mothers, experience depression and stress as part of the grief and sorrow connected with having a child who is not developing typically, and in connection with the burden of parenting a child whose difficult behaviour is sometimes impossible to regulate? Do they experience depression and stress under circumstances of a lack of social support and of adequate services, of being totally exhausted, of being socially isolated, or of ethical conflicts between the rights or interests of family members, that cannot be solved?

The aim of the present study was to describe the experiences of five couples who had a child with autism and learning disability, each of the children currently living in a group home for a period of nearly two years.

METHOD

Participants and settings

The five couples had endeavoured for years, in earlier contacts with the municipality, to obtain adequate home-based services for their children, so as to be able to manage the family situation, but had not succeeded. They then took the initiative together of arranging for a specialized group home in a building the municipality made available for this. Their major motive in taking this step was the aberrant and violent behaviour of the children, who were scarcely possible to manage in the family any longer. They cooperated with the municipality in the preparations made for establishing this home for the children and in recruiting the staff. The present researchers were contacted by the Department of Child and Youth Care and were asked to perform an evaluation study of this new group home, established initially in response to the requests of the parents. The parents were informed of the study reported here and of the fact that it was part of the evaluation study that had been requested. At the beginning of 2000, a first interview with each of the couples was carried out,; a second interview, with each of the parents separately, was carried out two years later.

During the first half of the year 2000 the children moved into the new group home one by one. They were ten to eleven years of age when the study began. The children, in addition to their autism, had a learning disability, moderate in one child, severe in three others and profound in the remaining child. Their verbal language was either considerably delayed or was absent and all lacked spontaneous seeking and sharing of enjoyment, as well as having little or no interest in other persons or in performing activities with others. They also showed a number of additional characteristics often found in children with autism, including hyperactivity, short attention span, impulsivity, violent behaviour towards others, self-injuring behaviour (head banging, biting their fingers, hands or wrists), high pain thresholds, disorders

of sleep or of eating rhythm, and either lack of fear or excessive fear. They were children who needed attention all the time.

Interviews

The research interviews were of a hermeneutic phenomenological type used as a means of exploring a problem and gathering experiential narrative material, able to serve as a resource for developing a richer and deeper understanding of some human phenomenon (van Manen, 1997, 2001). The specific aim was to develop a conversational relationship with the parents and discuss with them how they regarded their experience.. The basic question asked was: What is it like having a child with autism and a learning disability?

All the interviews were performed by the first author at the community-based Centre for Child and Youth Care, a place well known to the parents. The interviews were conducted in each case several months before the child was to move to the group home. The parents had never met the first author before and, to make the situation more comfortable for them, they were interviewed as couples. When the second interview, two years later, was carried out, the child was living in the group home. On this occasion, the parents were interviewed one by one. The interviews took about one and a half to two hours each.

Analysis of the results

The first author is a family therapist whose pre-understanding of the parents' situation is partly based on fifteen years of experience in the psychiatric treatment of vulnerable families in a psychiatric clinic for children and young people, some of the families involved having a child with autism and learning disability. The pre-understanding also derives from the experience of working as a research assistant together with the third author in a Swedish study of 37 families with a child who had an autistic spectrum disorder (Sivberg, 2002a; 2002b; 2003). In that context the author met parents suffering from anxiety concerning the future of

their child and experiencing exhaustion caused by the aberrant behaviour of the child and by a lack of social support and respite care. The second author has worked for many years as a clinical psychologist in child health care.

The analyses were conducted in a collaborative way, each of the authors making his/her own analysis of a text, the three authors then comparing the assessments they had made and arriving at a common assessment following discussion. Each author began by reading an interview text in its entirety to gain a sense of the life world of the respondent, that is, of the person's frame of reference. The transcript was read through then once again to uncover or isolate thematic aspects of the phenomenon: "parents' experience of having a child with autism and learning disability". In doing so, the following questions were asked: What phrases capture the fundamental meaning of the text as a whole? What is this issue an example of? What is the essence of the experience involved? Thematic formulations were made and were written down. The transcripts were then read through once more and each theme found in the text was analysed once again to see whether it provided a deeper and more reflective understanding of what the parents had experienced.

Ethical considerations

The parents were all informed that measures would be taken to fully protect the interests of their children. They were also informed of the design.

In such a study it is important to protect the integrity of the participants in a manner making it impossible for them to be recognised as individuals. The results will be presented in part as quotations by either a father or a mother. Nothing identifying the individual child is reported. In performing interviews of this kind it is important to be attentive to the fact that the interview situation can be difficult for the parents since their narrating can lead to their

experiencing their own vulnerability and sorrow. The study was approved by the Ethics Committee of the Faculty of Medicine at Lund University (LU 304-99).

RESULTS

Six themes could be identified in the interviews with the parents before their children moved to the group home. These themes are described below.

Grief and sorrow about not having a healthy and typically developing child

Some parents felt right from the start that something was wrong with their child. This was connected with a strong feeling of guilt. Many parents experienced their grief as being permanent, though possible to detach from, when the child was not at home. It increased when they were unable to control their child's aberrant behaviour. Other parents experienced grief most when they were in a situation of comparing their child's performance with that of healthy children.

A father: When he was younger, it was a terribly unhappy time for us. He was not the healthy child we wanted. That grief is permanent, but now when he gets worse it's stronger and more difficult for me to handle it as a parent than it was earlier.

Attitudes towards other persons with problems had changed

Some of the parents felt that since having a child of their own with disabilities, they had developed a deeper understanding for others who were faced with difficulties in their lives. Some of the parents also said that they had changed their attitude towards being more understanding of people generally and thinking of the equal value of everyone. One parent experienced this as a kind of personal growth.

A mother: I think that you learn a lot as a human being by having a child with disabilities. You mature as a person and you get a totally new perspective on life.

The aberrant behaviour of the child was sometimes not possible to regulate

The parents had a child that they had to keep watch on every second s/he was awake.

Sometimes the child behaved aberrantly towards others and sometimes s/he also behaved violently towards family members and towards other children. When this happened, the parents thought of the need for professional support. They experienced the stress of always being on guard and sometimes felt powerless, wanting to give up and withdraw.

A father: He has enormous outbursts of temper and has obsessions that his mother is exposed to particularly. He hits, throws things and bites himself. He's very violent. You can't divert his attention. It disturbs us a lot, the feeling of being so powerless.

Total exhaustion

Some of the children had serious problems with their sleeping rhythm, sleeping no more than a few hours a night, and during the day they were often hyperactive. Close cooperation between the parents was not enough to change this. The parents were suffering from severe symptoms of stress, such as exhaustion, feelings of being depressed, the experience of losing control, and cognitive deterioration, not only in the family but also at work.

A mother: It's been so difficult with him. I sometimes wonder what he really feels. He wakes up at night and screams. The only thing that helps is my sitting and holding him. I feel so tired, so tired all the time. He wakes up at five or six in the morning. I'm so tired I just cry.

Social isolation

Families living with a child behaving in an aberrant, hyperactive and impulsive way have a stressful situation at home. The situation often becomes worse if they are in a setting that the child is not accustomed to. For this reason, the parents often choose to stay at home. For these

parents the social situation has changed considerably, which can lead to social isolation, which in turn can increase their level of stress.

A mother: Our life is totally different now. Before [he was born] I had many friends and liked to socialise a lot and invite people to the house. But now it's not easy at all, and we haven't visited others to any extent either. Since if we do there's likely to be a battle after half an hour or so, it just isn't possible.

Siblings being affected negatively

The parents experienced the aberrant behaviour of the child affecting the child's siblings in differing ways. They felt sad that the child's violent behaviour made his/her siblings withdraw, that they got hit or that their things were destroyed, in some cases that siblings did not bring their friends home or that there was little or no time left over for the siblings. All of this could be an additional burden in a stressful home situation.

A mother: Since his sister always has to keep her door locked and always has to be on guard, we prefer not to leave him alone with her anymore. We never do that at all now. It's a kind of obsession he shows. Sometimes he can be very nice, and he doesn't fight all the time, but we never know when it's coming. He pulls her hair, screams in her ears, hits her and destroys her things. We always feel sad when this happens.

When the children had lived in the group home for two years, there were six themes that were found in the interviews with the parents. Four of the five children were living in the group home most of the time, whereas the other child spent as much time at home with his parents as in the group home. For this latter child the group home was used more for respite care, since the parents felt that this gave them sufficient support. The variation in the time the children spent at home with their families varied for the four children living basically in the group home from a few hours spent there each week to two days or so a week. The parents

who were very much satisfied with the group home felt very safe about the child being there and simply left the child there after s/he had visited at home with the family over the weekend. The parents who were less satisfied with the group home, however, preferred to accompany their child to the home and stay there, trying both to provide and to obtain information about their child so as to gain as much control as possible over the things their child was dissatisfied with there. At the time of these interviews there was one couple that was thinking of taking their child out of the group home. These parents felt that their child did not get enough of the kinds of activities he needed. The parents were interviewed one by one at this second interview. Again there were six themes that could be identified.

It was a relief for the family when the child moved to the group home

Two years after the child had moved there, the parents could report that the whole family was feeling better. Earlier, the parents had felt almost burned out, exhausted and scarcely able to manage anymore. Now, some of the parents felt able to be thoroughly rested, remarking that this was better for the child too when he came home for visits.

A father: I don't think we would have managed if we had had him at home. I don't know what the consequences would have been for the other children and for my relations with my wife, or anything for that matter.

Being in an ethically difficult situation when entrusting the child to others

Some parents hesitated considerably about leaving their child to others and most of them had a guilty conscience about it. They felt themselves to be in an ethically difficult situation in leaving their child to the group home. The parents had long been very tired and some of them had been totally exhausted, the siblings had been negatively affected and most of the parents felt that it was not possible to go and see friends any longer. Despite all of this they had ambivalent feelings towards leaving their child.

A mother: Leaving him was the worst thing ever. I've never been so ... I still feel very sad when I think about it. I cried 24 hours a day and I didn't dare call them to ask how he was doing until two days later. When I called, they said that he was having a very good time. I then felt it was right and since then I've never hesitated.

Satisfaction with the group home because of the child' improving

Most parents felt that their child was doing well and had improved in the group home. This was the most important aspect of their attitude towards the group home. Important too was their experience of being treated respectfully and politely and of the staff working in a pedagogical way with their child.

A father: For me, it's very, very important that he's pleased, but still more important that he is taken care of properly, although seeing that he's pleased is almost as important. He's making more progress both in the group home and at school than he is at home.

Parents not being satisfied with the group home

Some parents felt that their child did not want to return to the group home after visits at home with the family. This led to stress and anxiety on their part, wanting to know whether there was anything in the group home that was not good for their child. They came to the conclusion that there were too many changes in staff. Other parents were displeased at their child not having as many physical activities as they thought s/he needed. They wanted a stronger educational orientation and less nursing and for the children to be given more training.

A mother: I want to have complete control over what's being done, both during the day and at night. They may think I'm asking for too much, but it's my child and he's only eleven years old. There are too many people. I've asked for a schedule of who's working when, but I never

get one. My son feels sad when we return there, and I don't feel good at all if he doesn't feel good. I don't feel confident about it anymore.

Sharing experiences with other parents

All parents experienced the meetings organised by the group home as something valuable.

However, there was variation in the need they felt to share experiences with other parents and in the desire to involve other professional people.

A mother: We sometimes have meetings for the parents in the group home. We, who are the parents, know each other. I think that's good. We're a group and we often think in the same way when we talk with each other. I'd be glad to see more meetings for the parents, and perhaps with teachers or with a psychologist.*Hope for the future*

The parents had experienced their child's capability of improving. They hoped their child would show an increased independence, such as through acquiring the ability to spend more time without the staff. They also hoped their children could find meaningful occupations and other activities when they grew up, such as school or having a job. Regarding the group home, they had hopes of it becoming the permanent home for their child.

A father: I'm a little optimistic. I've got a feeling of ... if we find the right medicine, and that, when he gets past puberty, he'll go on to take one step after the other. He's doing well at school. If they rebuild the group home to form small apartments, he can spend more time by himself when he gets older. Perhaps he can find a meaningful occupation as an adult.

DISCUSSION

Today children with autism and learning disabilities live mostly with their families. Numerous studies have shown that parenting a child with autism can produce stress in the family (Morgan, 1988; Dunn et al., 2001). Before the families here found a place for their child in the group home they had made efforts for years to obtain adequate home-based services to

manage the family situation, but had not succeeded. Would it have been at all possible to provide adequate support for these families at home without transforming their home into institutions? If a family had to share their lives and control with staff members, , would the stress be less? Do some families need more respite care or a place in a group home for their child to prevent the parents from developing severe stress symptoms?

At the time they committed their child to the group home, the parents expressed, grief and sorrow at not having a healthy and typically developing child. Parents of children with special needs are likely to experience emotional reactions which are similar to those evoked by bereavement, when their child is finally diagnosed. The process of adaptation may be long and painful (Holland, 1996). Some parents in this study experienced their grief as being permanent, and others as its growing stronger when they found they were unable to control the behaviour of their child. Is grief and guilt something that all parents of children with autism and learning disabilities experience, or is it derived from the experience of being unable to regulate the behaviour of the child? Since part of normal parenthood is teaching one's child how to adjust to different situations in life, to mature and to become more independent, feelings of failure could be part of the grief.

The overall sense of grief was connected with the experience of having a disabled child who would never be able to live a normal life. The parents also lacked the possibility in the future of interaction with their child as a normal adult. The parents felt that after having had a child with autism their attitudes had changed in a way that made them more understanding of other persons with problems. This experience of empathetic feelings may have made it easier for the parents to share with, and support, each other during the meetings organised by the group home, as well as in other situations.

Before they obtained a place for their child in the group home, the parents had sometimes experienced a sense of total exhaustion. The parents of a child with disorders in their sleep rhythm (Schreck & Mulic, 2000) and with extremely violent behaviour towards others were those who suffered particularly from severe symptoms of stress, such as extreme fatigue, depressed feelings, the experience of losing control and cognitive deterioration. During this period of their lives, the parents were socially isolated. The aberrant or violent behaviour of their child, and their own extreme fatigue, were the main reasons for the parents not inviting others over or visiting them. The parents also felt that the siblings of the child could be negatively affected (Bågenholm & Gillberg, 1991; Rivers & Stoneman, 2003; Benderix & Sivberg, 2004). They felt sad at not being able to protect the siblings from getting hurt or having their things destroyed. These experiences also evoked feelings of failure as part of the parents' grief.

Two years later the parents found that, although it had been a relief to the family when the child had moved to the group home, they nevertheless felt guilty at having committing their child to others. They were in an ethically difficult situation (Banks, 2003), the dilemma between rationally doing the right thing when they decided to accept a place for their child in the group home, and emotionally doing the wrong thing, in handing over the care of their young child to others. Most of the parents were satisfied with the group home and thought that their child had improved. They also laid great importance on their child appearing to be happy or pleased. If the parents had feelings of failure in parenthood earlier, perhaps the burden of this feeling was relieved when they saw their child happy and pleased. However, some parents were dissatisfied with the group home. These were parents who found that their child seemed not to want to return to the group home after a visit to the family. Some also felt that their child's behaviour had changed for the worse, which caused stress and anxiety on their

part. These parents wanted to determine whether there was something wrong with the group home. Was the ethical dilemma increased (Banks, 2003) by their worrying and by their disturbing experiences of this sort?

All the parents appeared to appreciate very much the meetings held in the group home, yet not all of them felt free to talk about everything concerning their child. It was easier for parents who were very pleased with the group home to talk about emotional matters, such as concerning one child having hurt another child. All the parents had hopes for the future regarding the possibilities for their child to improve. Although some of the parents were not pleased with everything in the group home, they were hopeful for the future regarding the group home as possibly becoming a permanent home for their child. They all hoped their child would become more independent and receive lifelong school training or a meaningful daily occupation. Two years after the opening of the group home, the parents felt sufficiently confident about such matters to be hopeful regarding the future. Their experiencing this could be a sign of a sound mutual decision having been made by the parents and the municipality, one that provided these five families a place for their children in the group home.

CONCLUSION

The result of the study need to be considered tentative and be investigated further in studies of other families' experiences with group homes for fairly young children with autism and learning disabilities, and with aberrant and violent behaviours. However, for the present group of parents and siblings the group home seemed to be a relief, despite the burden on the parents of the ethical question: Are we doing the right thing?

The results also suggest that municipalities should reflect on the living conditions of families in similar situations and initiate a dialogue regarding their needs for home based services and

the possibilities of future sheltered housing. Regarding the latter possibilities, the current view that children with disabilities should not be separated from their parents should perhaps be questioned in the case of children with autism and learning disabilities.

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