

A matter of perspective: the experience of daily life and support of mothers, fathers and siblings living with children on the autism spectrum with high support needs

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Introduction

Much research has been undertaken examining the impact of living with autism on the family. However our understanding of life in families with children on the autism spectrum is predominantly based on research carried out with parents. Even when siblings are the specific focus of the study, parental report may be the primary data source (e.g. Griffith *et al.*, 2013; Hesse *et al.*, 2013). Furthermore it has been argued that fathers' perspectives are under-represented, and that mothers are often the primary or exclusive participant in this area of research (Cridland *et al.*, 2013; Flippin and Crais, 2011; Johnson and Simpson, 2013). This means that assertions are often made about 'families' or 'parents' based solely upon maternal report (Phelps *et al.*, 2009; Weiss *et al.*, 2013). Whether mothers' perspectives should be privileged in this way, and whether such reports can be assumed to represent the views of their spouses and children is debatable (Seligman and Darling, 1997). Whilst there is some emerging literature focused on mothers *and* fathers (Jones *et al.*, 2013; Pottie and Ingram, 2008) the need for more research focused within families, looking at all members, has been identified (Griffith *et al.*, 2013).

This study seeks to address this issue by investigating the experience of daily life and social support of fourteen families that include children and young people on the autism spectrum with high support needs. It has three main aims: (a) to identify the key themes within the narratives of mothers, fathers and siblings across these families; (b) to identify key factors emerging from the consideration of whole families' experience of living with autism; and (c) to consider the implications of these issues for research and practice.

Research design

Sample and data collection

Fourteen families from an English county were interviewed to collect data about daily life, family attitudes and informal/formal support. The sample was selected from a population of 150 families that had participated in an earlier study (Preece and Jordan, 2007) by considering a number of dimensions. The primary dimension was dependence: all families interviewed had children with high support needs, rated at 7/10 or higher on a dependence scale adapted from the work of Robinson and Stalker (1990). Further dimensions were family composition, location (urban, rural), ethnicity, child's educational placement and use of support services.

Data collection was a two stage process. Initial visits took place to meet the families, discuss the research and interview process and verify consent with all respondents. The interviews were conducted during second visits, about a week later. In total 32 semi-structured interviews were undertaken with 13 mothers/1 foster mother; 5 birth fathers, 1 stepfather, 1 partner and 1 foster father; and 10 typically-developing siblings – 4 brothers/6 sisters. Families were interviewed individually or together as they preferred. Interviews with parents lasted from 20 minutes to 2 hours (average = 45 minutes). Sibling interviews lasted from 5 to 40 minutes (average = 20 minutes). The children and young people on the autism spectrum within these families have also been consulted - this has been previously reported elsewhere (Preece and Jordan, 2010). Details of the families and interview process are given in Table 1.

Table 1 Details of the families consulted

Family	Details of individuals	Details of consultation
Family A	Mother (39), father (39) of two sons (14 and 12) on the autism spectrum.	Individual interviews.
Family B	Mother (48), partner (55), and sister (24) of young male with autism (16).	Individual interviews.
Family C	Mother (43) of 7 year old male with autism: interviewed alone.	Individual interviews.
Family D	Mother (43), father (40) and brother (10) of 13 year old female with autism.	Individual interviews.
Family E	Mother (45) of daughter (15) and son (13) on autism spectrum.	Individual interviews.
Family F	Mother (36) and stepfather (29) of 11 year old male with Asperger Syndrome.	Interviewed together.
Family G	Mother (43), father (50) and brother (9) of 18 year old female with autism.	Parents interviewed together. Brother interviewed with parents present.
Family H	Mother (40) and sister (18) of 15 year old male with autism.	Individual interviews.
Family I	Mother (38), father (42) and sisters (16 and 15) of 8 year old male with autism.	Individual interviews.
Family J	Mother (38), brothers (16 and 14) and sister (10) of 9 year old male with autism.	Mother and brothers interviewed individually. Sister interviewed with mother present.
Family K	Mother (36) of 10 year old female with Asperger Syndrome.	Individual interview.
Family L	Mother (34) and father (35) of 7 year old male with autism.	Individual interviews.
Family M	Mother (44) and sister (18) of 12 year old male with autism. Interviewed individually but with whole family present.	Individual interviews, but with all family members present.
Family N	Foster mother (63) and foster father (66) of 16 year old male with autism.	Individual interviews.

Ethical issues

Ethical approval was obtained from the University of Birmingham and the county's research governance board. Initial individualised letters were sent to all parents and siblings explaining the research – letters were differentiated according to children's ages. Consent was further discussed during the initial visits, and written consent was obtained from all persons interviewed. Throughout, consent was explicitly identified as an ongoing process (Miller and Bell, 2002) and participants could withdraw at any time.

Analysis

Data were transcribed and imported into NVivo, a computer-assisted qualitative data analysis software package (Bazeley and Jackson, 2013). A provisional set of key codes served as a template for the data analysis (Basit, 2003; Miles and Huberman, 1994) which included codes derived from Seligman and Darling's systems approach to childhood disability (1997) and Carver's work on coping (Carver *et al.*, 1989; Carver, 1997). Further codes emerged within the process of analysis. Substantive statements and themes were identified and condensed into matrices, which were constructed for families as a whole, and for mothers, fathers and siblings. A sample of transcripts and completed matrices was analysed by an independent auditor to ensure reliability.

Results

Key themes emerging within mothers', fathers' and siblings' narratives are identified, before moving on to discuss issues relating to the experience of whole families. All names have been changed.

Mothers' perspectives

Thirteen mothers and 1 foster-mother, ages 34 to 63 years, were interviewed. Nine were in paid employment, six were single parents, and all but one was the main carer in their family. One mother felt that – though undiagnosed – she may be on the autism spectrum, or that she at least displayed characteristics of the broader autism phenotype. Consistent themes emerging from their interviews are acceptance of the impact of ASD on their lives, isolation and stigma, concern about the impact of living with ASD on siblings and fear about the future.

Acceptance

In general mothers accepted the impact on themselves of having a child with autism. Resignation was common, with career and life aspirations having been curtailed to cope with day-to-day demands.

"I stopped beating myself up and just thought, the focus is the children and...that's annoying sometimes, and is limiting on my life, but I can't see any other way of doing it (Mother, family E)."

Weekday mornings typically followed set routines, coordinated to fit in with getting the child to school. After school, mothers were largely occupied in full-time interaction with the child. Getting the child ready for bed and settling them to sleep often took hours and in a number of cases the mother had to go to bed along with him/her. Weekends and school holidays were reported as even more demanding, especially by lone carers.

"Awful! Awful! Because that's when it's difficult on your own, because you're having to watch him every minute. It drives you crazy... (Mother, family C)."

Isolation and stigma

Isolation was a consistent theme, often beginning within the marital dyad. Half the mothers were single parents, receiving no day to day support from the father. Where fathers/partners were around, they were generally distanced from providing direct care. Many mothers also reported being isolated from the wider family; and a recurring theme was the loss of friendships and relationships formed before the child's birth. Instead, their friendships tended to be with other parents of children with ASD, formed through their children's schools or in support groups. While offering support, these relationships also enhanced their sense of isolation and separateness from the rest of society.

"I used to have quite a big circle of friends. Then we had Ian and I'd got this Tasmanian Devil in a buggy, and you lose an awful lot of friends awfully quickly, particularly when you say he smears poo! They don't want to know you anymore (Mother, family A)."

Stigma was also consistently identified. Hurtful and critical comments from complete strangers about their children's behaviour or their parenting were common. Even more debilitating could be the negative attitudes and behaviour of neighbours, such as petitioning the local council as they were unhappy about school transport parking in the street.

Concern regarding siblings

While most mothers accepted the impact of ASD on themselves, they worried about its impact on their other children. Some had other children with special needs – such as diabetes or learning disabilities – whose needs and difficulties were not sufficiently prioritised due to the demands of the child with ASD. Where the child with ASD had younger siblings, mothers wanted these siblings to experience as "normal" a childhood as possible. Regarding older siblings, mothers often felt guilty about their reliance on them for care and support.

Fear about the future

All the mothers spoke of how they feared for the future, how they felt unable to plan ahead, and of the conflicting emotions these feelings engendered in them. Some tried to live their lives on a day by day basis, giving little thought about what the future may hold. Others reported treating family life as an educational experience, and focused their lives on maximising their children's skills.

Fathers' perspectives

Five birth fathers one step-father, one foster-father and one partner were interviewed, aged between 29 and 65 years. Six worked full-time outside the home, one was unemployed due to disability and one was a full-time foster-carer. In three of the single parent families, mothers felt their ex-husbands may have been on the spectrum. Where fathers were present, one was awaiting a diagnostic interview for Asperger Syndrome (subsequently confirmed) and another felt he had a number of difficulties in common with his son. Only one

father was the main carer; the other fathers and partners had little involvement with the hands-on physical care of the children with ASD. Significant themes in the interviews with fathers/partners were withdrawal, minimisation of difficulties/use of humour and, again, fear about the future.

Withdrawal

Eight fathers were no longer present in the family household, and half of these had minimal or no contact with their ex-wives and children. Where there were fathers or male partners in the nuclear family, they were typically less involved than mothers with both day to day childcare and contact with the professionals involved with their child, such as schools and social workers. This reflects findings in other research. Flippin and Crais (2011), reviewing the literature regarding early intervention in autism, write of fathers being involved in only 3 out of 27 studies; while Jones *et al.* (2013) identify mothers as the primary caregiver in 97% of the 161 families in their study.

In the current study, one father, whose wife held a senior managerial position, was the primary carer for their children; but this situation was exceptional. Many fathers worked long hours, and/or had hobbies outside the family home. Often they were sole wage-earner in the family and viewed working and earning as their contribution to the family; some fathers however acknowledged their withdrawal as conscious.

"To be honest, I'd rather spend a day at work than traipsing round school with him (Father, family I)."

No fathers attended support groups or sought contact with other families in similar situations. They were more likely to seek information in impersonal ways, such as using the internet.

Minimisation of difficulties/use of humour

Whereas mothers strongly expressed how ASD had impacted negatively on their families and themselves, fathers tended to minimise the difficulties that their family faced as a result of the condition –

"I don't think we have any real problems, to be honest (Father, family L)."

– and recounting family life in humorous terms.

"All my workmates know about Andrew, but don't necessarily understand his condition...and I don't see much point in explaining. So I'll go into work and say 'Guess what he did yesterday? Trod on the hamster!' And they just laugh, and I laugh too (Father, family I)."

Uncertainty about the future

Despite the themes outlined above, fathers too were fearful and uncertain about the future. Some dealt with these feelings by seeking to live one day at a time while others sought control by carefully planning out their future.

"When he was first diagnosed as autistic...you spend the next six months worrying yourselves to death about it, and what's going to happen to him in later life...but...you'll just kill yourself if you do that. So I came to a decision where I wasn't going to worry too much about it. As long as he's happy today, and we're happy today, then we'll work on tomorrow when tomorrow comes (Father, family I)."

"I've worked my life around this, being able to pack up and spend time with Sarah, sort of semi-retirement – I might just work a couple of days a week – and if she hasn't got a job or whatever, or can't do anything, it won't matter. I'll have the time...I'll have all the time in the world then (Father, family G)."

Siblings' perspectives

Ten typically developing siblings were interviewed: four brothers and six sisters aged from 9 to 24 years. All but one still lived in the family home. Five major themes emerged in their narratives: Life with autism as normality/sibling bond, restricted opportunities, embarrassment and stress.

Life with autism as normality/sibling bond

All of the brothers and sisters interviewed accepted the presence of autism within their family as being that family's 'normality'. As in other studies (Hannah and Midlarsky, 2005), siblings often took responsibility for the child with autism, undertaking direct physical care, preparing meals, taking them out and about and babysitting. Sisters in particular took on a caring role. Siblings felt they had a good understanding of autism, and had often researched and presented on the topic for school projects. All siblings identified things they liked about the child with autism, and it was clear they felt a close bond with them. Some felt that their experience of living with ASD had been beneficial.

"It's made me stronger inside because it's given me something hard to cope with at a young age. So difficulties that I face later on will, I guess, be easier to get over... (Sister, family I)."

Restricted opportunities

Despite accepting life as 'normal', the presence of autism restricted the siblings' opportunities both socially and educationally.

"If I wanted to do something, it would always be, someone had to look after George...someone always had to be there for George (Sister, family H)."

As well as being unable to do things outside the home, siblings often could not have friends come to the home, either because the child with ASD would not tolerate their presence or because they were scared of the child's behaviours.

"If friends try to have a conversation with me they're interrupted and slapped. I think it's the aggression that makes it hardest for my friends. They can cope with the shouting, but they're just not expecting that (Sister, family I)."

Regarding educational issues, siblings spoke of homework being destroyed, or situations where they could not do homework due to the child with ASD's behaviour.

Embarrassment and stress

Despite the generally positive attitude towards their siblings with autism, they were often embarrassed by their behaviour. They also identified feeling high levels of stress: as well as their restricted social and educational opportunities, further stressors included aggression towards them and their personal space and possessions.

"It's a bit difficult sometimes. The thing I don't like is when people stare... 'cos it's obvious to me there's something wrong with him... 'cos of the things he does, and ...I just don't like people staring (Sister, family H)."

The experience of families

Analysis of the 32 interviews with the fourteen families identified five key themes relating to whole families. These were: the differing perspectives of mothers, fathers and siblings; limited access to informal support; wide range of adaptation and coping strategies; blurring of parental/sibling roles; and wide variation in experience of statutory services.

Differing perspectives

The results of the thematic analysis reported above support the assertion of Banks et al. (2001) that different individuals in the same family may have very different perspectives on the same situation and that different family members experienced and conceptualised the presence of autism in the family unit in different ways.

Limited informal support

Grandparents were the major source of support to many families. Even so, for half of the families, such support was unavailable, as grandparents were elderly or disabled, requiring support themselves; or were no longer alive. Some found support and acceptance of their families in church, while some mothers attended parent groups. Overall however families received only limited support from neighbours, friends or extended family. Relatives' fear or inability to deal with the child's behaviour and their lack of understanding of autism was highlighted by a number of respondents.

*"If I'm honest, I resent my husband's sister because she's c*** with the boys and she's quite judgemental about them (Mother, family A)."*

Range of adaptation and coping strategies

A range of ways of adapting to living with autism was demonstrated within this study. Some families, while not unaffected by the presence of autism, were able to achieve what they considered a normal family life. Some were embattled with the local authority, fighting for services. Others, such as family M (which had never sought formal support) had 'hyper-accommodated' to the presence of

autism. Asked about typical evenings with 12 year old Bill, his mother's initial description did not seem unusual.

"He has his tea more or less straight away, and watches a bit of telly, plays on his Gameboy...has a bath...and goes to bed. Once he's there, you could drop a bomb, and that's it (Mother, family M)."

Further questioning however identified that the family made significant accommodations to keep Bill happy. His mother cooked her own and his 'evening meal' in the mid-afternoon, and they ate at 4pm. From then until bedtime and beyond, his mother was with him constantly. Though he had his own bedroom, it was used only to store his clothes and toys; he slept in his mother's bed, with his mother, each night. His mother accepted this without demur. Furthermore, if ever Bill's mother visited her elder daughter's family in a nearby village, his 18 year old sister had to replicate her mother's routine.

"I have had him on my own at night...I have to go to bed when he wants to go to bed, which I don't like doing, obviously. He won't sleep in my bed or in his bed and he won't go to bed on his own if mum's not here, so I have to go to bed in mum's bed with him. It's a bit difficult (Sister, family M)."

Multiple and varied coping strategies, positive and negative, were used within all fourteen families. Most used problem-focused strategies such as planning, active coping and seeking instrumental support from a variety of sources: grandparents, a privately arranged childminder or statutory services. However, even having acknowledged the need for and accessed instrumental support, using it remained problematic. Family members spoke of guilt and uncertainty when the child was away, as well as concerns regarding how others viewed them.

"People that don't know us, I say my son goes to respite, and it's like then you're a mother that doesn't cope. You're not coping with your child so we're going to give you a weekend away (Mother, family A)."

Given this lack of both informal and statutory support and understanding – and taking account of other factors such as the impact of autism, the child's dependence and the routines and ways of adapting that had become norms – it is unsurprising that many families spoke of having a 'siege mentality', presenting and perceiving themselves as united against the outside world.

"We're sort of left out, aren't we? Which is probably what's made our relationship so strong, and ...you know, we love each other to bits, and we love each other's company all the time...and it's probably 'cos there's nobody else, is there (Father, family G)?"

Blurring of parental and sibling roles

Often parental and sibling duties were blurred, with siblings (particularly sisters) taking on caring roles. Turnbull *et al.* (2006) describe how they may be drawn into the parental subsystem, leading them to experience fewer parent-child and other sibling interactions, and causing their own needs as a child to be

subordinated and overlooked. This is described time and again and many parents were acutely aware of the blurring of roles, speaking of the guilt and anxiety it caused.

Wide variation in experience of statutory services

Families had varying experience of formal social care support, which was limited and difficult to access. Some accessed services such as short breaks (respite care) or young carers groups for siblings; others did not, either through choice or due to service shortfall. Though all families in this study had some experience of social work involvement, the mothers were the primary and often sole point of contact with professionals. Husbands and siblings were unclear about social workers' roles and functions, and many had never met their family's social worker.

"I've only seen her once, and she just sat there at the school review. What she actually does I don't really know (father, family D)."

Some families felt stigma attached to needing a social worker; others spoke of high turnover, which made building relationships difficult, and necessitated telling the same story again and again. While some families were enthusiastic about the support they received, many felt social workers had little understanding of autism, and that they made little effort either to get to know the child or to take account of family members' wider caring or work responsibilities. Numerous examples were recounted where families felt poor service exacerbated their difficulties. One family's short breaks stopped when the respite foster carer became pregnant. The mother (a single parent with four children, and no relatives in the country) requested that the service continue provided by another family; however almost a year later she found the social worker had not actioned this request and they were not even on a waiting list.

School can be a major source of support for families with children on the autism spectrum; and some families spoke of their satisfaction with their child's school, and of positive relationships. However problems were common, with school acting as yet another stressor impacting family life.

"They seemed to know all about autism, and be clued up...but in actual practice, they're not. So he's always getting told off, and generally he comes home from school in a state. Crying, upset and angry (Mother, family F)."

Discussion

This research supports previous studies that have highlighted the difficulties faced by families living with autism, and the range of stressors – internal and external – that impact upon daily living (Gray, 1998; Randall and Parker, 1997; Preece and Jordan, 2007) and identifies that daily life can differ considerably between families, and that there is a wide spectrum of experience and adaptation. It also supports findings in other areas of family research that show how mothers' reports on daily life can differ from those of fathers/partners (Pelchat *et al.*, 2003; Wang *et al.*, 2006) and their children (Guite *et al.*, 2004).

Consideration of the key themes emerging within the discourses of mothers, fathers and siblings identifies that though some themes are shared there are significant differences between different family members' narratives. So while both mothers and fathers alike expressed fear for the future they utilised different ways of dealing with the situation in the present. While mothers spoke of their acceptance of their situation and sought support, fathers were more likely to display withdrawal, to minimise the difficulties the family faced and to use humour. Such behaviours have been identified elsewhere as common masculine coping strategies (Alpass *et al.*, 2001; Gray, 2002; Sullivan, 2002); and Garner and Clough (2008) identify how males may typically mask their emotions and seek to remain externally positive or stoic in the face of adversity and grief.

Difficulty engaging fathers was an issue within the study itself. Six single parent households were included in the sample: in all of these the lone parent was a woman. While this generally reflects the situation in the population from which the sample was drawn (34 of the 150 families contained only one adult: 31 were mothers, 2 were fathers and 1 was a grandmother) the main reason no single father households were included is that neither father was willing to participate. A further father who had a caring role for his disabled wife and son with autism also withdrew from the research before the interview process began.

Researchers must seek to understand and acknowledge the differing perspectives that can be held by family members; and, crucially, so must practitioners. Carpenter and Towers (2008, p118) identify that

"support services for families focus primarily on the needs of mothers and are predominantly provided by women."

A range of issues can negatively affect fathers' relationships with services. These can include external factors (e.g. difficulty getting time off work), service factors (some settings have been typified as 'female spaces'), father characteristics (lack of self-esteem, feelings of intimidation) and practitioner factors, such as experience and awareness of masculine coping characteristics and behaviours (Carpenter and Towers, 2008; Garner and Clough, 2008; Sanders *et al.*, 2009). Burke (2010) further identifies the need for practitioners to identify, and act upon, the needs of siblings, who all too often experience 'disability by association'. Assessment of all family members' perceptions of daily life and support needs is essential if services are to be effective.

This should not be thought of as minimising the importance or veracity of mothers' perspectives. Mothers have been shown to be typically more involved in caregiving than other family members, and have increased vulnerability to being affected by the child's behaviour. Moreover the themes emerging from the mother's narratives – of isolation, resignation and stigma – stand in stark contrast to some recent maternal studies that have focused on positive outcomes of parenting disabled children (King *et al.*, 2011; Trute *et al.*, 2010). Knight (2013) suggests that focusing on maternal resilience and positivity risks minimising the challenges they face, as well as potentially creating a restrictive image of the caring and capable 'good mother'; and the findings here highlight the difficulties that mothers (and families) continue to face in navigating daily

life. One mother spoke of how professionals had praised her for her parenting skills and positivity; however, she said,

"...they don't see how it is. They don't see me when I'm p***ed off and sitting on the floor crying (Mother, family A)".

Overall, this study identifies that a range of perspectives exist within families and between family members. A family-centred focus, taking account of all family members' perspectives, will help researchers and professionals alike to understand better the impact of living with autism on all concerned.

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