

# Under the radar and behind the scenes: the perspectives of mothers with daughters on the autism spectrum

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## Editorial comment

This paper highlights the paucity of research that focuses specifically on girls with autism and in particular on the perspective of their mothers. Linda Eaton has a daughter with autism and in this paper reports on a study she undertook towards her degree in autism, with 19 mothers who also had a daughter with autism. A postal questionnaire was completed seeking their views on diagnosis, needs and services and on the demands and rewards of having a daughter on the autism spectrum. The findings suggest that diagnosis often occurs well after the point at which their mothers expressed concern, that useful information on autism and on how best to support their daughter was often not provided by professionals and that parent support groups were a better source. Services, support groups and the literature too had a focus on boys with autism, and there was far less specifically for girls. On the positive side, many mothers spoke of how much they had gained from their daughter and the rewards the experience brought. There is a growing recognition that more research needs to be done on the different needs of females with autism and on the most relevant and appropriate information and services for parents and the girls and women themselves. This paper will lend support to this.

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## Introduction

*'As a mother you naturally want to do the best for your child and there is a lot of pressure for early intervention. This panicked me a little as I thought that if I haven't done something drastic before she is 5 she would never reach her full potential.'* (Ashley, 2007 p 22)

Individual accounts, such as Karen Ashley's above, bestow us with insights about life with an autism spectrum daughter and demonstrate the need mothers feel to be pro-active in their daughter's development. With the increasing number of children being diagnosed on the autism spectrum, a growing body of literature is emerging from the parental perspective, but these often

feature the parenting of a male child. In my experience, despite increasing awareness of girls on the autism spectrum, it seems that the voices of their mothers are rarely heard. Certainly, all mothers with children on the autism spectrum face challenges, but for those with daughters, one could argue these challenges are magnified. This paper therefore focuses on the mothers' perspectives of their daughters on the autism spectrum. What are the challenges and rewards for these mothers? As the mother of a daughter diagnosed on the autism spectrum, I have more than a little affinity with other mothers, including those in this study. It is hoped that their participation has allowed them the opportunity to express their perspectives, both positive and negative in nature.

## Review of the literature

In recent years, more females are being identified as being on the autism spectrum than was the case in the past (Gould & Ashton-Smith, 2011), although it is still the case that boys are more likely to receive a diagnosis, even when the severity of the difficulties are held constant (Russell, Steer & Golding, 2010). Girls on the autism spectrum are considered to be more social than males (Gillberg in Frith, 1991) and can experience more anxiety (Hartley & Sikora, 2009). Females remain under-researched though (Klin, 2007 in Bazelton, 2007), and often lack support (Gould & Ashton-Smith, 2011) and services (Ernsperger & Wendel, 2007). Girls are often omitted entirely from research studies (Nichols et al, 2009) as they may 'skew' the data (Klin, 2007 in Bazelton 2007). So, research conducted almost entirely with parents of boys, has been used to form the basis of interventions, diagnostic criteria and understanding. Ernsperger & Wendel (2007) argue that much of the research in the field of autism has assumed gender is irrelevant. But is this the case? Can we assume that the needs of girls are sufficiently similar to those of boys and that they are likely to respond in a similar way to interventions or are there important differences that should be taken account of and deserve separate study?

From descriptions of being 'cold and unfeeling' (Bettelheim, 1967), mothers have historically been blamed for their child's autistic condition. Despite this view being discredited (Rimland, 1964), theories such as Bettelheim's had a far reaching influence and the resulting impact for mothers cannot be ignored. Some claim this influential view still exists (Hingley-Jones, 2005) and that mothers have been fighting this ever since (Stace, 2010). Yet research has shown that far from being 'cold', mothers of children on the spectrum are proactive (Kuhn & Carter, 2006), they seek information (Mansell & Morris, 2004) and show remarkable strength (Montes & Halterman, 2007). The paradigm shift away from 'mother blame' has prompted research into these care providers' perspectives to assist professionals in developing support and interventions (Burkhardt, 2001).

The literature has shown that mothers of children with autism do experience substantial stress (Bristol & Schopler, 1984; Bristol, 1987; Gray, 1994) and are in receipt of more blame than others for their child's behaviour (Anderson, 2007). Mothers who have a daughter on the autism spectrum frequently fulfil a multitude of roles. Besides providing support for their

daughter, they are also wives, have a home to run, have paid jobs and are usually mothers to other children and may have their own parents to support too. They can therefore be physically and emotionally exhausted and so it is extremely important that they are given timely and appropriate support so that demands are lessened rather than added to. However, they may find themselves accused of over anxiety by professionals when seeking diagnosis (Grinker, 2007) and are often still held to account or stigmatised (Gray, 2002).

Researching the literature on the mother–daughter dyad in autism proved problematic as there is little specifically on this topic. As primary care providers, mothers have a direct impact on their daughter's development, and it is argued that the most formative relationship in a female's life is that of the relationship between mother and daughter (Rich, 1976). Traustadottir (1991) suggests that mothers are 'expert witnesses' and need to be recognised as such so that their knowledge and experiences are not invisible.

## Sample and methods

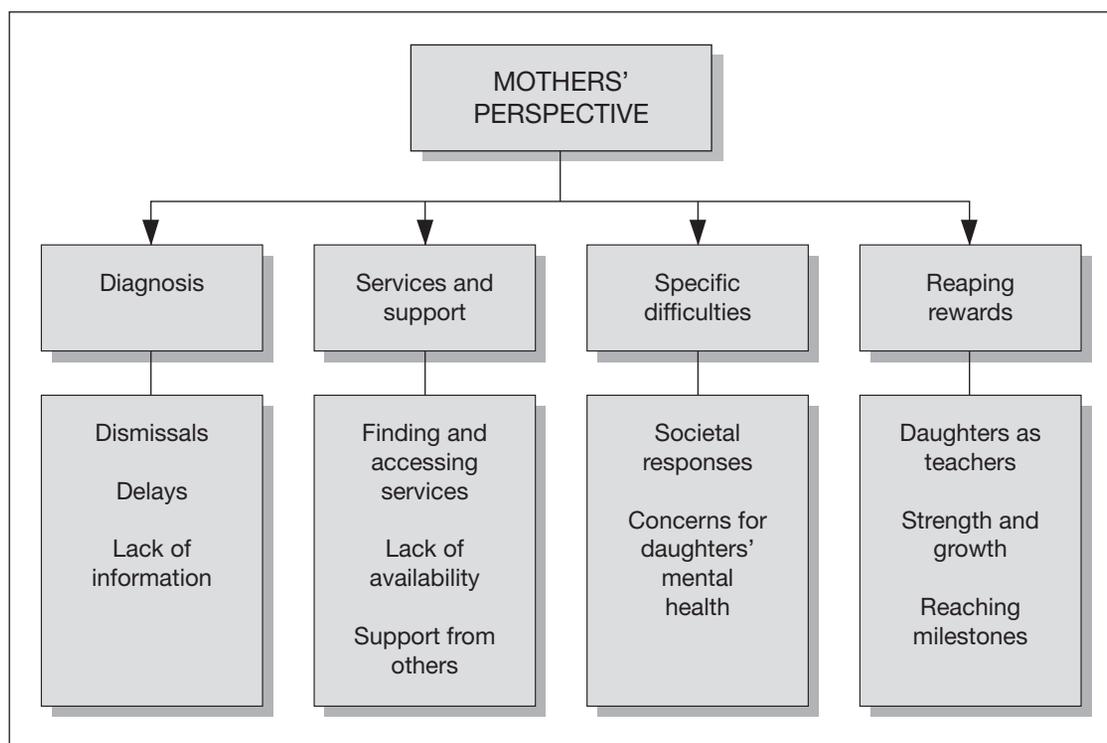
A local autistic society was contacted and asked for mothers who were willing to take part in the study. Within 24 hours, 11 mothers had replied indicating their willingness to participate. This increased over the course of just one week to a total of 30 respondents. Due to time and budgetary constraints, interviewing all respondents was not possible so data were collected using a questionnaire. All participants were happy to express their views in this manner and were sent the questionnaire in the post. Of 22 sent out, 19 were returned which is a very high response rate for postal questionnaires. Ethical issues were considered and strictly adhered to. All participants were advised of their right to change their minds at any point of the study and were assured that identifying information would be anonymised before being viewed by others. Personal data were destroyed on completion of the study and consent to publish this paper obtained.

## Findings

*Figure 1* summarises the four main themes that emerged from the questionnaires. These will each be discussed in turn.

## Diagnosis, dismissals and delays

All 19 mothers (100 per cent) had concerns about their daughter's development prior to diagnosis, which



**Figure 1:** Mothers' perspectives on bringing up daughters on the autism spectrum

occurred at an average age of eight years. Almost half of the mothers felt their views were not valued or taken seriously by those professionals involved. Mothers who answered positively spoke of finding professionals who were good listeners and had been supportive, even if not fully knowledgeable about autism. Others considered professionals actually viewed them as part of the problem.

*'[I] was told [it was] "separation anxiety" ... get on with it!'*

*'... it was suggested that I was simply over concerned since I was a first time mum ...'*

*'I think professionals actually tend to blame the parents.'*

*'they ... blamed her anxieties on me.'*

For many, diagnosis brought validation for their daughter's behaviour, and provided 'evidence' to present to disbelievers. Some were concerned that delays negatively affected their daughters in terms of lost time.

*'... if she had the support and guidance at 3 [years old] then she wouldn't be having so many problems now ...'*

*'I have been asking for help since she was 3 ... I worry that it's too little too late.'*

*'[Concerned] that given the delay in diagnosis and not having support early ... she won't achieve her true potential.'*

### **Lack of female-specific information**

Most mothers realised that early support and intervention were crucial, although the majority received very little information at diagnosis. Many found that information related to boys, and did not reflect the nature of their daughter's condition.

*'We were given a booklet and sent away ... I feel dumped now.'*

*'There was nothing ... they dropped the bombshell ... that was it ...'*

*'...at the time I found nothing that explained why she just sat so quietly ... hitting? aggression? ... hissy fits ... no, just calm aloneness ...'*

*'Why can't we have a package for Mums, a girl specific one ... just so much to take in [diagnosis] and then having to seek out information ... well it's too much ...'*

## Societal responses

A major problem was one brought about by the 'hidden' nature of their daughter's condition. Eight mothers described this as one of the most difficult aspects of parenting a daughter on the autism spectrum.

*'My daughter's autism is almost hidden at times, she spends ... time controlling herself.'*

*'Other people don't accept that her symptoms are genuine.'*

*'The public are so quick to judge and comment on [her] behaviour.'*

*'Being believed ... as girls are more quiet and compliant ...'*

*'They think I am making excuses when her responses appear "naughty".'*

*'Many have the view that if their perception of classic autism isn't immediately evident, then the girl does not have autism ...'*

*'She doesn't stand out in a crowd ... so you'd never guess she had autism.'*

## Concerns for their daughter's mental health

Eight of the participants discussed problems such as crying, self-harming, low self-esteem, depression, suicidal thoughts and phobias experienced by their daughters. Whilst distressing for most, for others this had escalated to serious levels.

*'As a Mum I want nothing more than for her to stop self-harming.'*

*'I hate hearing her tell me she is a horrible person and friend.'*

*'She begs us to kill her and put her out of such misery.'*

*'Anxiety ... she is acutely aware of her difficulties and there is a feeling of helplessness.'*

*'... it's heartbreaking to think she's so confused and unhappy ... she clearly needs help.'*

Additionally, four mothers did not consider specialist services were able to help with their daughter's difficulties.

*'... CAMHS (were a) disaster-openly admitted they didn't understand autistic girls.'*

*'... the psychologist told me she didn't know girls could get it [autism]...'*

*'... she [daughter] hated going there [name of service provider]. She couldn't handle the way the therapist sat so close to her, and hated all the eye contact.'*

*'She's low down on their "priority list" ... she's not likely to punch anyone, so she just suffers inside ...'*

## Services and support

Mothers were asked whether the diagnosis had led to support and services for their daughters. Responses to this question were varied with three mothers stating it had not. Ten mothers felt that it had, three mothers said not and the remaining five mothers said that although it had provided access to services, they still encountered problems.

*'... better access yes, but outcomes not necessarily significant.'*

*'... in theory yes ... in practice ... still fighting.'*

*'... marginally ... it has given us more "ammunition".'*

Two respondents said diagnosis had allowed access to other ways of helping their daughters that they would not have had before diagnosis:

*'I went on the "Earlybird" course ... it helped me understand her condition.'*

*'... been on an Introduction to autism session which has helped me understand her difficulties better.'*

In terms of satisfaction with the services on offer, just under half the mothers with daughters aged from 5 to 9 years (eight girls) were disappointed with the range of services, or they discovered that services were often male dominated.

In the older age group (daughters aged 10 to 17 years), three quarters of mothers were not satisfied as criteria for access were often 'strict' due to funding limitations and as their daughter appeared as more able, this often meant they were ineligible for services.

*'I feel I've struggled alone with various issues [services], as autism is more "boy" related ...'*

*'Autism in girls is so different ... she comes across as a lovely well balanced person ...'*

*'... you have to fight to be seen ... so only a parent with "oomph" ... will be heard. You have to be pushy ... which adds to the stress ...'*

*'constantly fighting for help ... being told ... "we don't fit the criteria".'*

*'[they say] "we are a needs-based service" ... [I'm told] she doesn't need it as much as some'*

One mother described that whilst social opportunities were available, these needed to be 'facilitated' by someone with knowledge of autism. Without such facilitation, opportunities were useless. Others described how they purposefully encouraged activities for their daughters in order to foster social skills.

*'She is a homebird ... she finds going out difficult.'*

*'I have to "fabricate" social outings for her ... there's nothing girl specific in this area.'*

*'... [she] struggles but is getting better at it with practice.'*

*'I make sure she has lots of social opportunities ...'*

*'I am looking at other facilities for [name of child] to try ...'*

### **Accessing support**

Most mothers expressed the need for, and value of, support for themselves and their daughters, but finding support was challenging. Although family members were generally reported to provide good support, three mothers said they received little support from their family and friends and one mother said she had met with hostility from her family, whom she felt did not accept the diagnosis. Several respondents felt the most beneficial support came from 'informal support' provided by other parents and volunteer groups.

*'I feel that much of the support I receive is ... through volunteer groups ...'*

*'... joining this [name of local service] group has been a life saver to me.'*

### **Daughters as 'teachers'**

Mothers felt they had learned resilience and strength through fighting for their daughters. They accepted their role as advocate on behalf of their daughters and expressed admiration of their bravery to face life in the world around them. Descriptions included the closeness shared and the joy they felt when their daughters were happy. Participants spoke with pride; describing positive qualities to their daughters' personalities such as uniqueness, honesty and genuine acceptance of other people. Some spoke of a strong sense of justice along with a good sense of humour or they related humorous incidents. Not only were these traits seen as rewarding, they were also considered aspects that other people could learn from. Achieving often minor milestones were considered rewarding, even those that would appear insignificant to others.

*'... she has no prejudices and accepts everyone ... a trait I believe a lot of people could learn from.'*

*'She ... is a great person to have a conversation with.'*

*'... the simplest steps ... insignificant to others but to us are milestones.'*

*'... I am a better Mum because of her ...'*

*'Learning about her difficulties has enabled us to establish a very strong bond.'*

### **Discussion**

Howlin & Moore (1997) found the average age for a diagnosis of autism in the UK was 5 years, and despite improvements since, mothers in this current study demonstrate that little has altered for these girls whose mean age at diagnosis was eight years. Gould & Ashton-Smith (2011) suggest that unenlightened diagnosticians perceive able individuals, with good conversational skills as not fulfilling the criteria set out in international diagnostic systems; therefore diagnosis is missed. This was a concern as mothers felt that early diagnosis potentially alleviated many difficulties for girls on the autism spectrum and contributed towards a better quality of life for them. In terms of suggestions for improving the time frame, one mother simply proposed

that professionals should ‘... believe the mother ... assess the girl’. Ironically, mothers noted that often their daughters had self-knowledge of their difference, and their diversity was also evident to their peers, but they were not recognised as different by professionals and so did not receive a timely diagnosis. Unfortunately, maternal experiences of not being believed are not uncommon and lend support to previous research (Simone, 2010), that mothers are often ‘seen as part of the problem rather than the solution’. Constant frustrations with views being dismissed often meant that mothers lost confidence in those very professionals whose job it was to support them. Even mothers who had experienced positive interactions with professionals, often felt frustrated that specialist input stopped at diagnosis, leaving them with tenuous access to less knowledgeable individuals. For many, diagnosis produced relief, validated their concerns and allowed them to move forward.

Following diagnosis, the study found mothers often received little professional assistance and this is consistent with findings by Osborne & Reed (2008). This lack of input surprised mothers who said they expected a flood of information and future appointments with specialists. What they received was often very little or nothing. The revelation that mothers of younger girls were somewhat more satisfied in general (as they expressed more positive responses to questions about support), could be explained by the recency of the diagnosis or that services are improving. It may also be the case that for the mothers of older daughters, services are less appropriate or less readily available or may be an indication of the increased difficulties as girls mature, particularly towards puberty (McClennan, Lord & Schopler, 1993).

A common theme was the belief that many service providers and professionals thought that girls with autism were more able than boys. Mothers were concerned that this was mistakenly translated as ‘in need of less support’. The lack of role models for their daughters was an area of concern for some. In terms of learning their identity, it could be crucial that they have access to meeting other girls on the autism spectrum. But the current findings suggest that this is rarely offered.

Nyden, Hjelmquist & Gillberg (2000) argue that girls may actually be in more need of support than boys; indeed specialist services and programmes are vital to helping

girls improve their self-esteem (Annear, 2006). In the current study, most mothers described services that were male oriented or male dominated and particularly unsuited to their daughter’s needs. However, whilst many spoke of how their daughters preferred the company of either younger or older children, three mothers said their daughters preferred the company of boys.

The mothers’ reports on the benefits of parental and charity groups is consistent with previous research by Renty & Roeyers (2006) who found formal support less effective than informal support, particularly in terms of reducing stress. Whilst all mothers in the current study were members of such a group, it is noted that mothers of older daughters expressed the most satisfaction with support gained in this environment. Again this could not be fully accounted for but these mothers may have found a valuable network for gaining information and acceptance from others (Starke & Moller, 2002) and they may have greater need for such support as their daughters’ problems increased with age.

The topic of mental health whilst not specifically addressed by the questionnaire was cited by mothers as one of the most challenging aspects of raising their daughters. These findings are consistent with other research. Studies by Kopp & Gillberg (1992) found girls on the autism spectrum exhibit more anxiety as they grow older, whilst McClennan, Lord & Schopler (1993) found girls’ anxieties increased particularly in middle school age. In the current study however, daughters described as having mental health problems covered the whole age range from 5 to 17 years. Participant responses are comparable to research by Lainhart & Folstein (1994) who found that despite the gender ratio of the autism spectrum, females represented half of those in the medical literature in terms of mental health difficulties. The mothers harrowing comments regarding their daughters mental health, suggests a critical need for specialist services with fully trained professionals and highlights the need for interventions for girls that foster self-management of stress and anxiety and assist in developing coping strategies. Such skills have been reported to be vital by Koegel & Koegel (2001) for the individual to recognise and reduce their own levels of stress.

Rutherford (2007) has suggested that the hardest part of living with autism is not being believed. Indeed, findings

from the current study identified several challenges directly related to the hidden nature of the condition where mothers had to convince others of their daughter's needs. Whilst this concept is by no means new, the findings suggest that others often held expectations beyond these girls' abilities or meant that others did not make accommodations for their daughters. It was also surprising that some found their daughter's condition remained indiscernible to family members; whilst 'trying to persuade them' of the girl's problems, they were often accused of fabrication. Naturally, this placed a strain on those mothers who were then unable to turn to their families for respite or support. Ironically, the hidden aspects became quite apparent in the community when behavioural episodes such as melt downs or tantrums, produce looks and comments from members of the public. These findings are consistent with previous research (Gray, 1994; Read, 2000; Rocque, 2010; Thompson & Emira, 2011) and suggest that the nature of autism often means that members of the public interpret certain behaviours as manifestations of personality rather than to a specific condition.

At the heart of any autism spectrum condition is a distinct social difficulty (Hobson, 1993; Trevarthen et al, 1996), making it difficult for mothers to have 'girly conversations' with their daughters, yet participants described other rewards. Previous research by Bromley et al (2004) found mothers developed patient qualities as positive aspects to their care provider role. In the current study, mothers saw the experience of raising their daughters as making them better individuals; suggesting growth develops through adverse life experiences. Previously, research has also described mothers who can positively adapt to their child on the autism spectrum (McCubbin, 1993), and who maintain close relationships despite stress they endure (Hoffman, Sweeney, Hodge, Lopez-Wagner & Looney (2009). Mothers in the current study showed they viewed their daughters as teachers, and felt benefited insofar as they were rewarded with a far richer aspect to their lives.

The role of advocacy became palpable in descriptions of fighting that mothers to secure diagnosis and services for their daughters. Responses correspond with Ryan & Runswick-Cole (2008), who emphasised that for mothers with children on the autism spectrum, their role as advocate and activist is a major part of their experience but is also largely unrecognised. Rocque

(2010) insists that mothers interpret their child's behaviours in order to help others understand their autism condition and in the current study mothers needed to undertake this role to explain their daughter's condition in order for them to be accepted. This was clearly a characteristic adopted by the mothers as a means to obtaining services and upholding rights, as one participant described 'you need oomph'. The mothers' ability to 'fight' often results from their maternal instinct and their confidence and ability to know their daughter's needs. This may be a contributory factor in the growth that they described. For these mothers, they have used their intimate knowledge of their daughters to communicate with others and raise their own self confidence. Mothers were frequently keen to share their joys with other people. As Rocque (2010), suggests mothers therefore help their daughter to construct a 'positive identity'. It may be argued then, that for these mothers of girls on the spectrum, this role was undertaken not simply through choice, but also out of necessity.

### **Concluding comments**

This study found that mothers with daughters on the autism spectrum encountered several difficulties related directly to the hidden nature of the condition. This frequently left their maternal skills in question by those who viewed their daughter's behaviours as a product of personality or parenting rather than a component of a lifelong condition. It appears that mothers of daughters experience similar challenges which affecting mothers of all children on the autism spectrum. Their experiences may be no lesser or greater than others, but are compounded by the unique difficulties facing females on the spectrum. These are that their girls with autism may appear more socially able and may be more compliant than boys. They are more likely to imitate what their peers are doing and so may not stand out. But, as Yaull-Smith (2008) suggests, this 'copying behaviour' is exhausting for girls on the spectrum and their efforts are not always seen and therefore acknowledged by members of the public or professionals. Having a child on the autism spectrum has been described by Stace (2010) as a challenge but not a tragedy. Certainly the mothers in this study also have the enviable position of finding another unique aspect to their lives. They were humbled by their life journeys so far with their daughters, rich in knowledge and honoured to be sharing their lives with their daughters, who have much to teach us. The endearing qualities and traits demonstrated by these

girls show they have much to offer in terms of being daughters, mothers, friends and valued members of society.

Recommendations therefore would include the need for care providers to be furnished with female specific information and resources at the point of diagnosis and beyond. The findings support the importance of those helping professionals involved to listen to maternal concerns and when unsure, to refer on in order for a more timely diagnosis. Mothers' descriptions of their daughters mental health problems implicate the importance for targeted provisions delivered by professionals with expertise in autism and interventions for girls that foster self- management of stress and anxiety and assist in developing coping strategies. Participant accounts imply further research is required that identifies services for girls on the autism spectrum.

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