# “I received a leaflet and that is all”: Father experiences of a diagnosis of autism

# Accessible summary

* Little is known about what fathers think and feel about a diagnosis of autism.
* Fathers experienced strong emotion around diagnosis and were given little support.
* Services should support mother and fathers in ways which meet their individual needs.
* More positive messages should be given to families at diagnosis.

# Abstract

A diagnosis of childhood autism can be an extremely stressful experience for parents but little is known concerning paternal perceptions of the process. This study investigated father perspectives on a diagnosis of autism, through an online survey. An analysis of 184 replies to an open ended item identified the following themes: strong initial emotional response and a range of immediate anxieties about the future, struggle to gain a diagnosis; anger in response to insensitive delivery of diagnosis together with insufficient information at the time and lack of support afterwards. Findings are discussed in relation to gender-differentiated approaches to service delivery and models of disability.

# Background

Parenting children with disabilities is acknowledged as demanding (Beresford et al., 2007), with the parenting of children with autism recognised as particularly challenging, due to the wide range of difficulties which children can experience (Fiske, Pepa, & Harris, 2014). Receiving a diagnosis of autism, therefore, can represent an extremely taxing experience for many parents, sometimes resulting in depression (Taylor & Warren, 2012). Furthermore, the diagnosis itself may often come only after a prolonged period of frustration, anxiety and delay. In a study of over a thousand UK parents, Crane et al., (2015) found an average three and a half year delay in receiving a diagnosis from first contact with services. Somewhat surprisingly, no reduction in delay was in evidence since the previous large-scale UK study by Howlin & Moore, (1997) and this was suggested as being possibly due to the higher incidence of Asperger syndrome in the most recent sample, a diagnosis which has traditionally been more difficult to make due to the possibility of characteristics being confused with those of other disabilities (Kosger, Sevil, Subasi, & Kaptanoglu, 2015). Neither had levels of satisfaction with post diagnostic support increased in the intervening period, in fact rather the reverse, with 61% of parents expressing dissatisfaction in the recent study (Crane et al., 2015) compared with 37% previously (Howlin and Moore, 1997), attributed by the authors to possibly increased expectations within the autism community and most especially those who had experienced a positive experience of the diagnostic process.

Furthermore, Crane et al., (2015) reported that one third of parents expressed dissatisfaction with diagnostic delivery while Harnett, Tierney, & Guerin, (2009) found that four in ten parents of children with disabilities did not believe that the news had been delivered with “hope and positive messages” (p.261). Such a situation is concerning since the manner in which a diagnosis of childhood disability is communicated may have significant implications for parents’ ability to cope in future. In a study of 85 families, Taanila, Jarvelin, & Kokkonen, (1998) found that parents with poor experiences of the diagnostic interview were five times more likely to experience insecurity and helplessness than those who were satisfied with it, noting later (Taanila, 2002, p. 1289):

the first information and the way it is presented can shape not only the image the parents create about their child and his/her future but also their prospects for the functioning and future of the entire family.

Although early support following an autism diagnosis is considered essential for better child outcomes and the reduction of parental stress (Keen & Rodger, 2012), in practice, there is often considerable delay. Crane et al., (2015) found that 35% of parents received no offers of support at all.

Father experiences of a diagnosis of childhood disability are under-reported in the literature. In one rare study, Hornby, (1992) reviewed the published accounts of eight fathers, reporting on often intense emotional reactions to the news. In the field of autism, parental perspectives on diagnosis have largely been confined to quantitative studies undertaken with mothers. For example, participants in the largescale study by Crane et al., (2015) were largely female (93%), comparable to the proportion of mothers (92%) taking part in Casey et al., (2012)’s study of post-traumatic stress following an autism diagnosis. Similarly, in Alba and Bodfish's (2011) research on addressing the concerns of parents at the time of diagnosis, only 7% of respondents were fathers. Studies which do include a small number of men in almost all cases do not disaggregate results by gender, either because numbers of fathers were too small or the gender of participants was not known.

Reasons for father exclusion in the literature have been variously suggested as men being considered hard to reach in research terms (Phares, Rojas, Thurston, & Hankinson, 2010) stereo-typical gender-based assumptions concerning child-rearing roles (Flippin and Crais, 2011) and/or lack of flexible timetabling of data-collection to take account of men’s employment (Fabiano, 2007). Braunstein et al., (2013) argued that gender-blind studies make an implicit assumption that gender is not a relevant variable in analyses, which in turn drives a tacit conjecture that findings reported in respect of mothers will apply equally to fathers, which is often not the case. For example, Papageorgiou & Kalyva, (2010) found that mothers and fathers of children with autism differed significantly in their stated needs and expectations in respect of support groups.

Braunstein et al. (2013) contested that the under-representation of father perspectives negatively affects the ability of service providers to support them since they are lacking evidence-based guidance on men’s needs and contribution. Here, since parental experience of diagnosis appears to influence on-going perceptions and attitudes (Taanila, 1998), it seems important to explore paternal perspectives to better inform support both during and after a diagnosis of childhood autism. The research question to for this study was:

What are father reactions to gaining a diagnosis of autism?

# Methods

## Procedures

Fathers of children with ASD resident in the UK were recruited to an online survey in several ways. A web link was e-mailed to over 80 local autism voluntary groups who forwarded it to their members and web links appeared on national autism-related sites. Hard copy fliers were distributed at two national autism events and sent to several autism specific schools. An advert was placed in a nationally distributed autism specific publication.

The survey provided information on research aims, instructions for completion and contact details for the researcher.

### Instrument

Data were collected through an online survey which consisted of 52 closed and 5 open-ended questions. Its development was informed by relevant research tools, including the Inventory of Father Involvement (Hawkins et al., 2002), the Brief COPE (Carver, 1997) as well as on previous research studies, including Towers’ work on fathers of children with developmental disabilities (2006; 2009).

This paper reports on responses to one open-ended opportunity for fathers to comment on their response to their child’s diagnosis, phrased as follows: “if you would like to tell us about your experience of diagnosis, we have included a space for you to do that here.”

### Participants

The sample completing the survey were 306 fathers of children up to 19 years of age, with a diagnosis of autism, autism spectrum disorder or Asperger Syndrome and resident in the UK. One hundred and eighty four fathers (60% of the total sample) responded to the open ended question concerning perspectives on diagnosis. Characteristics of the whole sample are provided in Table 1 and those of the subset responding to the open-ended question under discussion here in Table 2. This sub-sample is largely representative of the wider sample. The most note-worthy difference was that 58% of the subsample was educated to degree level or above compared to 52% in the whole sample. Most fathers responding to the open-ended question were white (94%); over 40 years of age (81%); married (82%) and with one child with autism (87%). The majority of participants were in full-time paid employment (60%), with just over half (58%) educated to degree level or above. In respect of children, 81% were boys, 52% were aged 10 or under and 48% aged between 11 and 19. Regarding diagnosis, 30% of children had a diagnosis of autism, 41% one of ASD and 29% a diagnosis of Asperger Syndrome.

**Insert Table 1 about here**

**Insert Table 2 about here**

# Data analysis

Data analysis consisted of initial *a priori* coding to broadly categorise responses according to the phase of diagnosis to which they referred: that is prior to, during and following diagnosis. This approach was informed by the literature where there is a focus on stages to clarify aspects of the complex set of parental experiences involved in the diagnostic process (see Crane et al., 2015, for example). At the second level, a line by line inductive thematic analysis of 184 responses was undertaken to identify conceptual categories within each stage, for example, in relation to the delivery of diagnosis, a strong theme relating to emotional response emerged, together with perspectives on support offered at diagnosis. Representative quotations were then chosen from each of these second level themes as illustrative exemplars.

# Ethics

Ethical approval for this research was given by Leeds Beckett University. Fathers were given assurances of confidentiality and anonymity and were informed that survey completion would be taken as consent. To provide some benefit from taking part in the study, fathers could opt to receive a summary of findings from the survey and 80% (n=245) did so.

# Findings

Information concerning the length of responses to the open-ended question is provided first below, followed by a detailed discussion of individual themes, presented in relation to the stages of the diagnostic process. Each illustrative quotation is followed by pertinent characteristics of the father concerned and his child/ren, to contextualise the data: specifically, the father’s age group and level of qualification, together with the child’s age group, diagnosis and age at diagnosis.

## Response length

Responses concerning reaction to diagnosis varied in length, between 1 and 153 words, with the mean length of statement 24 words. The shortest statements were often powerful: “cried”, “angry, isolated”. The longer responses discussed a complex range of issues, reflecting on past and future concerns or the support available after diagnosis.

## Concerns before diagnosis

Over 1 in 4 fathers (n=51) commented on prior concerns regarding aspects of their their child’s behaviour, so that when the diagnosis came it was not unexpected. However, comments ranged from an awareness that there was an issue: “was not surprised as we had felt for a while something was different” to almost complete certainty that their children had autism: “It confirmed what we knew”.

## Process of getting a diagnosis

Seventeen (9%) fathers commented on the process of getting a diagnosis. Most had found the process overlong, difficult and frustrating, requiring significant amounts of on-going pressure from parents:

The process was long, laborious, and tiresome, with very little give from the local diagnostic team.

(Father, 21-29, degree; child, 3-5, ASD; age at diagnosis, 3-5)

We had to fight every step of the way to get the diagnosis.

(Father, 40-49, degree; child, 6-10, ASD; age at diagnosis, 6-10)

Only one father commented positively on the gaining a diagnosis, describing it as “straightforward”.

Although nine in ten fathers did not choose to comment on the process of getting a diagnosis, this cannot be taken to indicate that their experience was necessarily stress free. It may be that other aspects of the diagnostic experience were more salient for them.

## Experience of the delivery of diagnosis

Eighteen (10%) fathers, only one of whom had also commented on the process of getting a diagnosis, remarked on aspects of the delivery of the diagnosis itself, generally expressing dismay at the manner in which the news was conveyed. For some, the process was lacking in sensitivity and understanding:

My wife and I were told matter of factly "your son has autism, he may never speak". It was devastating.

(Father, 40-49, degree; child, 6-10, ASD; age at diagnosis, 3-5.)

We were just asked “Have you ever heard of autism?" and then left to get on with things as best we could. It was as well for our sanity that we did not realise at the time the extent to which the diagnosis would change our lives.

(Father, 60-69, degree; child, 11-14, ASD; age at diagnosis, 0-2)

A number of men’s responses expressed implicit anger at the bluntness of the delivery of the news:

Your child has asd - here's some leaflets!

(Father, 30-39, vocational training; child, 6-10, ASD; age at diagnosis, 3-5.)

It was "your son's autistic - off you go". The NHS is appallingly bad/incompetent/neglectful about autism

(Father, 50-59, degree; child, 6-10, autism; age at diagnosis,

3-5.)

Only one father commented positively on the experience of diagnosis, appreciating the way in which the doctor helped him to reflect on the ‘labelling’ aspect of the process:

I think I was stunned even though I was not surprised. But I took on board the doctor's statement that a label changed nothing about the way he is but it did enable access to greater levels of support.

(Father, 40-49, degree; child, 3-5, ASD; age at diagnosis, 3-5)

Crane et al., (2015) reported that two thirds of parents were satisfied with how the diagnosing professional had conducted themselves during the diagnostic interview, although only 7% of participants were fathers and no gender-differentiated analysis was undertaken to clarify commonalities or differences in perception in this key area of the diagnostic process.

## Emotional response to the diagnosis

Just under half of fathers (49%, n=89) described an explicitly emotional reaction to receiving the diagnosis. Many statements were brief but described strong reactions.

Cried

(Father, 40-49, completed secondary school; child, 11-14, ASD; age at diagnosis, 6-10)

Devastated

(Father, 50-59, Degree; child, 15-19, autism; age at diagnosis: 3-5.)

I was gutted

(Father, 30-39, Passes at ‘A’ level; child, 6-10, ASD, age at diagnosis, 3-5.)

The diagnosis was a hammer blow

(Father: 40-49, degree; child, 11-14, Asperger syndrome; age at diagnosis: 3-5.)

It was like being hit by a moving train

(Father, 40-49, completed secondary school; child, 11-14, Asperger syndrome; age at diagnosis, 6-10)

A number of fathers described a range of strong emotions

Upset, demoralised

(Father, 50-59, vocational training; child, 15-19, age at diagnosis, 11-14).

Denial, grieving, frustration

(Father: 40-49, Degree; Child: 6-10, ASD; age at diagnosis: 0-2.)

Different emotions and different stages is the best way to describe it, guilty, angry, upset, heartbroken, fearful, anxious and confused to name a few

(Stepfather: 21-29, Degree; Child: 15-19, Asperger syndrome; Diagnosis: 11-14)

My personal reaction was to panic. As the dust settled panic led to an array of emotions including fear, worry and general negative feelings for his future.

(Father, 40-49, ‘A’ levels; child, 3-5, ASD, age at diagnosis, 3-5

For most fathers who had mentioned prior concerns, the diagnosis when it came still caused substantial distress:

We already knew he had autism so the diagnosis was simply confirmation. Nevertheless it was a highly emotional moment.

(Father: 30-39, Degree; Child: 3-5, autism; Diagnosis: 3-5)

Four fathers talked explicitly in terms of loss, both in the present and in the future:

I felt like I had lost my child's future and was losing aspects of being a parent. Might never be a grandparent, send him to university etc...

(Father: 40-49, Degree; Child: 6-10, Autism; Diagnosis: 3-5)

For example, it is noteworthy that a number of fathers (n=23, 13%) whose children had been diagnosed with autism for at least five years chose to focus on their strong emotional response to the diagnosis in their comments, giving some further indication of the strength of the sentiment at the time. Additionally, the emotional nature of fathers’ responses did not seem to be related to any particular diagnosis. A large proportion of the 86 fathers of children with Asperger syndrome completing the survey, expressed a strong negative emotional response to diagnosis, as illustrated in the representative quotations provided above. Nor did fathers’ educational level appear to be associated with the reporting of such a response.

## Initial anxieties

Fourteen fathers (8%) described their early anxieties following diagnosis, especially in relation to the future. Fears for children’s safety, especially when parents were no longer alive, were particularly evident:

Very little knowledge of autism, wondering how can I protect him?

(Father, 30-39, degree; child, 3-5, ASD; age at diagnosis, 3-5.)

I was scared. Worried what kind of life she would have particularly when I am gone.

(Father, 40-49, vocational training; child, 6-10, ASD; age at diagnosis: 0-2)

I looked into the life expectancy

(Father, 30-39, GCSE’s; child, 6-10, ASD, age at diagnosis, 3-5.)

Some fathers described a range of anxieties concerning the kind of difficulties their children might experience. Uncertainty was a key aspect of one father’s apprehension:

To this day I have never been given an expectation of how my child will develop, what he will achieve, how much dependence he will have etc. Not knowing can made it hard to develop a long term plan.

(Father: 40-49, degree; child: 11-14, Asperger syndrome, age at diagnosis: 3-5)

Fiske (2009) reported that reminders of the long term nature of a diagnosis of autism was associated with higher levels of stress in fathers compared with mothers which resonates with the focus on the future by some fathers here.

## Benefits of diagnosis (this section has been moved)

Twenty seven fathers (15%) highlighted relief as a major response to the diagnosis, often since it explained troubling aspects of their child’s behaviour which they had not been able to understand previously:

There was some relief through having an explanation for behaviour and confirmation of suspicions

(Father: 50-59, degree; child: 15-19, Asperger syndrome, age at diagnosis: 6-10.)

Although it wasn't good news, I mainly felt relieved, to know that my experiences was not down to being a bad parent. It enabled me to be more prepared and understanding of the symptoms

(Father: 40-49, vocational training; child: 3-5, autism; age at diagnosis: 3-5.)

Several fathers felt relieved because a diagnosis would help them to provide more appropriate support for their children:

Having a diagnosis meant that we could start understanding his condition and how to manage it.

(Father: 40-49, degree; child: 11-14, ASD; age at diagnosis; 3-5.)

I think it was good to have the 'label' because with the label we could access other services.

(Father: 50-59, Degree; Child: 6-10, ASD; Diagnosis; 3-5.)

Two fathers talked about their children’s own responses to the diagnosis:

My son is very very proud to have Asperger’s - always has been and he tells people this.

(Father: 50-59, completed secondary school; child, 11-14, Asperger syndrome, age at diagnosis: 6-10.)

My son needed it to be able to be sure and put a label on it. Since the diagnosis, he has been happy talking about it outside of the home.

(Father: 40-49, degree; child: 6-10, ASD, age at diagnosis, 11-14.)

Russell & Norwich, (2012) reported on parental perceptions of the benefits of a diagnosis of autism in a qualitative study of 17 parents, only two of whom were fathers. Here a larger group of men, whose children have differing autism diagnoses, identify benefits with an emphasis on the empowering aspects of such news, for them in relation to gaining a better understanding of their children and the greater potential for access to services and in a few instances for their children in achieving greater self-awareness.

## Impact on relationships

The responses of twelve fathers (7%) specifically referred to differences or similarities in approach or response between themselves and their partners at various stages of the process. One father and his wife had disagreed about the need for a diagnosis:

I resisted the process as I didn't want to label my child but my wife and the paediatricians didn't respect my wish to not have him assessed.

(Father: 40-49, GCSE’s; Child: 6-10, autism; Diagnosis: not given.)

Two fathers reported that they and their partners were not together when the diagnosis was received. Other fathers described a difference in initial reaction to the news:

Having had two older children we knew something was wrong so I had prepared myself for the diagnosis - my partner took it hard but we worked together we realised that it was about doing what we could do for our son.

(Father: 30-39, GCSE’s; Child: 6-10, autism; diagnosis: 3-5.)

Another man commented on the strain he experienced in trying to support his wife through the stressful experience:

It was a difficult issue to deal with…My wife was very upset by the diagnosis so it was important for me to maintain a positive attitude throughout which did put a strain on me.

(Father: 40-49, degree; child: 6-10, ASD, age at diagnosis, 0-2)

For one father the news of diagnosis had a particularly severe impact on his relationship:

Discovering that my son had autism came as no surprise but nevertheless it rocked myself and my then wife to the point of separation.

(Father: 40-49, ‘A’ levels; Child: 3-5, ASD. Diagnosis: 3-5)

Findings from the wider survey, from which the current data set is drawn found that over half of all fathers (52%, 161/306) felt that having a child with autism had negatively affected their couple relationship (Potter, forthcoming) resonating with the results of a meta-analysis which found relationship satisfaction amongst couples having children with autism to be lower than amongst those having children without disabilities (Sim, Cordier, Vaz, & Falkmer, 2016). The year following diagnosis has been reported as imposing particular stresses on couples (McGrew & Keyes, 2014) and here, insights into the kinds of pressures which diagnosis placed on relationships are provided from the paternal perspective.

## Father exclusion

Nine fathers felt that they had not been sufficiently included in the process of diagnosis due to a greater focus on their partners’ needs:

It was shocking and very depressing. Most people concentrated on my wife's distress not mine.

(Father: 50-59, degree; child,15-19, autism, age at diagnosis, 0-2.)

I felt unheard - all the focus was on his mum.

(Father: 50-59, vocational training; Child: 3-5, autism. Diagnosis: 3-5)

I was kept out of the assessment and diagnosis by my ex. The clinicians made no attempt to contact me.

(Father: 40-49, degree; child: 6-10, Asperger syndrome; age at diagnosis: 6-10)

There is . a general prejudice against fathers: the assumption is that daddy is either absent or useless.

(Father, 40-49, degree; child, 11-14, autism, age at diagnosis, 0-2.)

Although the numbers of fathers choosing to focus on feelings of exclusion during the diagnostic process were relatively small, such comments can be contextualised within wider survey findings, where 60% of the whole sample completing the survey (185/306) reported that they had not felt adequately supported “as the child’s father” in the period following diagnosis (Potter, forthcoming).

## Practical response

Twenty fathers (11%) focused in their responses on the positive steps they identified or took after diagnosis, including information seeking, course attendance or in a few instances, setting up services:

My first reaction was to get as much information on it as I could

(Father, 30-39, degree; child, 3-5, autism, age at diagnosis, 3-5.)

Upset but it was like an SLR (single lens reflex) camera lens coming into focus. I then read the Attwood book on Asperger's and it all became very clear. I attended some [local] events then felt I had enough knowledge.

(Father: 40-49, degree; child: 15-19, Asperger syndrome, age at diagnosis 3-5)

I was surprised, but I read all the books I could…I learned a lot, especially from ABA therapy.

(Father: 60-69, degree; child: 11-14, Asperger syndrome, age at diagnosis, 0-2)

Findings from the wider research associated with this study showed that “coming up with strategies for what to do” was one of the most frequently reported approaches to coping of fathers of children with autism (Potter, forthcoming). Furthermore, the increased use of information-seeking as a coping strategy amongst fathers of children with autism, compared to fathers of typically developing children was identified by Rodrigue, Morgan, & Geffken, (1992). Such findings have implications for service providers in relation to the nature of support which could be offered at diagnosis, discussed further below.

## Support after diagnosis

More than a fifth of fathers (n=39) talked about the significant lack of service support following the diagnosis:

We felt cast adrift by a very poor support structure.

(Father: 60-69, Degree; Child: 15-19, autism; diagnosis: 3-5.)

Following my son's diagnosis, I received a leaflet and that is all. Any help and support I have subsequently received, I have sought out and paid for myself…. This is an area where the NHS is sorely lacking.

(Father: 40-49, Degree; Child: 6-10, autism; diagnosis: 3-5)

I was given the diagnosis but absolutely no advice on where to go to get any help or support…the initial months after the diagnosis were very bleak.

(Father: 30-39, Degree; Child: 6-10, ASD; diagnosis: 6-10.)

Only one father described a positive experience of post diagnostic support:

Without the help of the professionals, I would have found it difficult after the diagnosis, but they showed me the right direction where I could get more training and help on understand autism and how to deal with my son to understand his needs.

(Father: 40-49, Degree; Child: 6-10, autism; diagnosis 3-5).

In this research, there appeared to be some relationship between educational level and comment on lack of service support following diagnosis, with 75% (29/39) of men doing so educated to degree level or above. This aligns to some extent with previous research which showed that higher educational and socio-economic status was associated with greater service use in families having children with autism (Thomas, Morrissey and McLaurin, 2007). The issue of access to services following diagnosis is clearly key.

# Discussion

This study extends our knowledge by reporting on the perspectives and experiences of 184 fathers on a diagnosis of childhood autism. The direct views of this group of parents very rarely appear in the literature in a field where mothers outnumber fathers by 8 to 1 as research participants. Fathers commented on a range of issues, including the process of gaining a diagnosis, the manner of diagnostic delivery, their often strong emotional response to the news, as well as on the lack of support and information provided at the time and afterwards. It was also evident that some fathers’ had not felt sufficiently included in the process.

The nature of many paternal concerns regarding delays and lack of support are generally consistent with those reported in the wider literature which is largely based on maternal experiences, as discussed above (see Crane et al., 2015; Howlin and Moore, 1997). However, the stark intensity of many fathers’ response to the diagnosis is consistent with findings discussed by Hornby’s (1992) small scale qualitative study of eight fathers’ responses to a diagnosis of childhood disability. Here the powerful and challenging experiences of a larger group of men is reported in relation to a diagnosis of autism, providing some further insight concerning relationships between characteristics of father background, the nature of children’s diagnoses and response to diagnosis. The strength and depth of emotional reactions reported is concerning when set alongside the significant lack of support which six in ten men identified post-diagnosis, in the wider survey from which the current data set is drawn (Potter, forthcoming). A key issue here is that the lack of effective support at such a critical time may influence men’s future ability to cope with family challenges which in turn may impact whole family functioning and relationships (Glenn, 2007). This seems especially important in relation to parents having children with autism who have been found to experience significantly more stress than parents of typically developing children or parents of children with other kinds of disability (see Hayes & Watson, 2013 for a meta-analysis). Towers (2009) highlighted that service providers should be aware that fathers and mothers may respond to a diagnosis of childhood disability in different ways and that therefore post diagnostic support could be offered to them as a couple or separately.

It is argued here that approaches to supporting men during and after diagnosis could usefully be informed by research investigating men’s help-seeking behaviour. In a review of 51 studies, Hoy, (2012) found that notions of masculinity negatively impacted men’s willingness to seek support. In the light of such findings, Oren et al., (2010) argued that a strengths based approach to counselling fathers, focusing explicitly on their ability to nurture and care for their children, may be a more effective approach to recruiting men to support services. Smith (2006) noted that the shift towards a strengths based, positive psychology model in the field of counselling represents a major move away from a medical, deficit model paradigm to an assets based approach, grounded in the prevention literature. She suggested that a capacity based strategy begins from the assumption that clients possess a range of existing strengths in areas such as knowledge, skills, emotional dispositions (including optimism and hope) and character (including courage and perseverance) as well as sufficient resources to learn new skills to address further challenging situations. Stages of strengths based counselling include developing a therapeutic alliance, identifying strengths, assessing challenges and instilling hope. While such capacity driven approaches may be especially effective with men, in the light of evidenced problems with help-seeking, they may also be productive with mothers. A review of literature in the field of positive psychology undertaken by Rao & Donaldson, (2015) concluded that although women were over-represented as participants in research studies, there had been relatively little focus on gender specific issues in relation to them. Further research in relation to strengths based approaches to service provision for fathers and mothers of children with disabilities is clearly indicated.

The manner of delivery of diagnosis also emerged as significant for a number of men in terms of undue brevity, lack of sensitivity and an emphasis on negative issues. There are two issues here. First, the degree of understandable anger expressed by men is particularly noteworthy in the light of Tower’s (2009) contention that the relationship between fathers and professionals is moulded around key events, one of which is diagnosis so that an overly negative experience at this critical moment may exert a considerable impact on the future pattern of father relationships with professionals. Second, an undue focus on deficits and future negative outcomes reported here and in other studies in relation to a diagnosis of childhood disability (see Hedov, Wikblad, & Annerén, 2002 and Harnett, Tierney & Guerin 2009) is problematic for several reasons. Most significantly, as indicated above, information conveyed at diagnosis can affect perceptions concerning the family’s ability to cope, with Taanila et al., (1998) reporting that feelings of being poorly prepared to care for their child were reported four times as often by parents dissatisfied with the diagnostic interview as those who were satisfied. Furthermore, a negative appraisal of the diagnostic experience has been found to be a strong predictor of increased marital burden (Stuart & McGrew, 2009). McLaughlin et al., (2008) conceptualised the process of diagnosis as being driven overwhelmingly by a medical/tragedy model discourse, where deficits and poor outcomes are foregrounded and it is argued here that such an approach not only undermines families’ at such a critical moment but also fails to take account of evidence of family resilience and benefits, increasingly discussed in the literature. Nissenbaum, Tollefson, & Reese, (2002) made a series of recommendations for practitioners delivering a diagnosis of autism, one of which related to the need to provide hope and optimism within a family friendly setting. Findings from the wider study associated with the current research reported on a range of positive perspectives identified by nearly two hundred fathers associated with parenting children with autism, including valuing children’s personal strengths, as well as fathers’ own nurturing role and what they had learnt from it (Potter, 2016). Such evidence-based, hopeful messages can and should be included in the diagnostic meetings, approaches to the delivery of which could be enhanced by further gender-differentiated training for staff in this sensitive area.

Lack of adequate information was a key concern for many fathers in this study and this is consistent with findings reported by the SCIE (2005) which noted that for many fathers obtaining accurate information on the nature of provision available for children and families was an especially important issue in the period immediately following diagnosis. It is suggested here that services might usefully consider the development of targeted online sources of information, sensitively tailored to meet the urgent and specific requirements of mothers and fathers struggling with a newly received diagnosis. The argument for consideration of an online approach in this area is strong, since according to most recent figures, 96% of households with children have access to the internet (ONS, 2014). Online information might be especially user-friendly for fathers who are often less able to access face to face provision available during the working week (Cutress & Muncer, 2014) and who may prefer online support and information ( Seymour-Smith, 2013). Professionally developed online parenting support has been found to be highly effective in supplementing traditional face to face services (Niela-Vilén et al., 2014). However, to date such resources have been largely targeted at mothers of younger, typically developing children to address early parenting skills and health topics (Nieuwboer, Fukkink, & Hermanns, 2013).

The lack of inclusion experienced by several fathers in the diagnostic process can be contextualised within findings from the wider survey associated with this study (Potter, forthcoming) where six in ten fathers felt that they had not been adequately supported “as the child’s father” in the period following diagnosis. Such perspectives are suggestive of a deficit model approach implicit in the attitudes of practitioners encountered and is consistent with findings from other studies in the field of disability where provision has been found to be generally targeted at mothers (see Flippin and Crais, 2011; McLaughlin et al., 2009; SCIE, 2005; Towers, 2009). Meadan, Stoner, & Angell (2015) conceptualised the functioning of families having children with autism within a family systems framework (see Turnbull et al., 2011) in which cohesion is seen viewed as vital to healthy family functioning, where cohesion is defined as “the degree to which members are “motivated to remain part of a group” (Schermerhorn, Hunt, & Osmond, 2000, p. 203, cited in Meadan et al., 2015). Father inclusion in the diagnostic process seems especially important since from a family systems point of view, such a stressful experience is likely to represent a considerable challenge to family cohesion in the immediate and longer term.

Limitations associated with this study should be noted. The sample of fathers cannot be said to be representative of all fathers of children with autism since the backgrounds of participants were relatively homogeneous with regard to ethnicity, level of education and marital status. While the response rate to the open-ended item under discussion is comparatively high (60% of the whole sample), nevertheless those who did not respond may have provided a range of differing perspectives**.** In addition, there are acknowledged limitations in the use of qualitative data gained through open-ended survey questions since as Jackson and Tochim (2002) observed, the brevity of such responses can serve to decontextualize experiences and perspectives and cannot provide the richness and depth of data gained through interview approaches. However, as many quotations reported here illustrate, such data can be powerful as a result of the necessary distillation of thoughts and feelings. Furthermore, it has been argued that the use of such questions gives greater voice to participants, especially relevant here in relation to fathers of children with disabilities whose perspectives rarely appear in the literature and may help to redress the balance of power between the researcher and the researched (O’Cathain & Thomas, 2004). In addition, for some fathers, diagnosis occurred some years previously bringing into question issues of accuracy of recall, although it has been argued that long term memory is significantly enhanced by strong emotion (Ahn et al., 2015), of the sort, it is argued, described by many fathers in this study.

# Conclusion

Fathers in this study reported a range of strong emotions and challenges during the diagnostic process within a context where most felt unsupported, indicating that much greater provision is required in this key area for both parents. Implications for service provision is that support should be gender-differentiated and strengths-based, taking account of the particular needs and perspectives of both mothers and fathers at this critical juncture in family life. In addition, more hopeful, evidenced-based messages should be sensitively communicated during and after the diagnostic interview to help develop a more balanced narrative where hopeful possibilities concerning the future for children and families are set alongside potential challenges.

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**Table 1: Characteristics of whole sample (306 fathers)**

*Characteristic* *N (%)*

*Age*

21-29 11 (4%)

30-39 51 (17%)

40-49 159 (52%)

50-59 77 (25%)

60-69 8 (3%)

*Number of children with autism*

1 257 (84%)

2 40 (13%)

3 8 (3%)

4 1 (1%)

*Relationship to child with autism*

Biological father 287 (94%)

Step-father 13 (4%)

Adoptive father 4 (1%)

Foster father 2 (1%)

*Marital status*

Married 242 (79%)

In a partnership 38 (12%)

Separated/Divorced/widowed 21 (6%)

Single 5 (2%)

*Educational background (highest level)*

Completed primary/secondary school 26 (9%)

Passes at GCSE/ A level 61 (20%)

Vocational qualifications 59 (19%)

Degree/ postgraduate qualifications 160 (52%)

*Employment status*

Full-time 190 (62%)

Self-employed 42 (14%)

Retired/ Not in paid work 46 (15%)

Part-time 27 (9%)

*Ethnicity*

White 286 (95%)

Mixed heritage 6 (2%)

Black or Black British 5 (2%)

Asian or Asian British 2 (1%)

Chinese 1 (1%)

\*Percentages may not total 100 due to rounding

\* Some values were missing.

**Table 2: Characteristics of 184 fathers responding to the open ended item**

*Characteristic* *N (%)*

*Age of fathers*

21-29 7 (4%)

30-39 27 (15%)

40-49 94 (52%)

50-59 47 (26%)

60-69 6 (3%)

*Number of children with autism*

1 158 (87%)

2 16 (9%)

3 6 (3%)

4 1 (0.5%)

*Sex of child*

Boys 146 (82%)

Girls 33 (18%)

*Age of child*

0-2 1 (0.5%)

3-5 22 (12%)

6-10 73 (40%)

11-14 45 (25%)

15-19 40 (22%)

*Diagnosis of child*

Autism 54 (30%)

Autism Spectrum Disorder 73 (40%)

Asperger Syndrome 54 (30%)

*Father relationship to child with autism*

Biological father 170 (94%)

Step-father 7 (4%)

Adoptive father 3 (2%)

Foster father 1 (0.51%)

*Marital status*

Married 147 (81%)

Living with partner 19 (11%)

Separated/Divorced 11 (6%)

Single 3 (2%)

*Educational background (highest level)*

Completed primary/secondary school 11 (6%)

Passes at GCSE/ A level 38 (21%)

Vocational qualifications 27 (15%)

Degree/ postgraduate qualifications 105 (58%)

*Employment status*

Full-time 106 (59%)

Self-employed 25 (14%)

Retired/ Not in paid work 29 (16%)

Part-time 27 (9%)

*Ethnicity*

White 167 (94%)

Mixed heritage 5 (3%)

Black or Black British 3 (2%)

Asian or Asian British 2 (1%)

Chinese 1 (0.5%)