

“I accept my son for who he is - he has incredible character and personality”. Fathers’ positive experiences of parenting children with autism

Abstract

Literature in the field of autism is largely deficit driven, with a focus on the inabilities of individuals and the negative experiences of families, often characterised by reductive assumptions and tragedy model interpretations. In addition, family orientated research has generally overlooked the views and contribution of fathers of disabled children, with positive paternal narratives especially scarce. This study explored 198 father perspectives on perceived benefits of parenting their children with autism gained in response to an open ended question in an online survey. Key themes relate to appreciating children’s individual qualities; valuing the strong emotional bond, fathers’ own nurturing role and their associated personal development. Findings will be discussed in relation to models of childhood disability and fatherhood.

Key words: fathers; autism; positive experience; models of childhood disability; models of fatherhood.

Background

The experiences of parents of disabled children are largely characterised by a range of reductive assumptions (Goddard et al. 2000) and tragedy model interpretations (Fisher and Goodley 2007) where negative aspects of parenting disabled children are foregrounded. McConnell et al. (2014) observe that due to such culturally ingrained belief systems, parents of children born with impairments are expected to demonstrate grief rather than more positive emotions and to begin a process of “remedying the problem”. Lalvani and Douglas (2013) argued that an assumption that parents will experience psychological distress as a direct result of difficulties associated with their child’s impairment has underpinned a deficit model approach which has informed both research aims and methodologies in relation to these families. In particular, they noted that the views of families having children with disabilities do not often appear in research, as their experiences are “reduced to statistical analyses of negative outcomes”. (2013, 9)

In their analysis of the portrayal of mothers of disabled children in the literature, Ryan and Runswick-Cole (2008, 200) highlighted how deficit model beliefs and attitudes serve to exert negative impacts on both children and parents:

“In an ‘abilist’ society, parents may be acutely aware of the devalued ‘bodily capital’ of their children, and the stigma with which the parents are also ‘tainted’ by virtue of their parenting relationships”.

Tragedy model approaches are especially prevalent in the field of autism, both in relation to children and families. There has been a strong focus on the demands of caring for children, with an emphasis on negative repercussions for family life. Causes and levels of parental stress have been explored (Allen, Bowles, and Weber 2013; Casey et al. 2012); the impact of stress on parental health (Kiani, khodabakhsh, and Hashjin 2014; Hartley et al. 2012) and stress and parental coping (Dabrowska and Pisula 2010; Pisula and Kossakowska 2010). The fact that parents of disabled children experience significant stress is not in doubt. Fathers reporting positive parenting experiences here also identified a number of major challenges and stressors within the same study. Specifically, over half of men responding (n=166) to

the online survey from which data for the current research is drawn, reported feeling stressed for “quite a lot” or “most” of the time and identified major stressors as the demands of caring for their child with autism, insufficient service support, concern about the future, the management of challenging behaviour, negative public attitudes and lack of sleep or rest (see Potter, forthcoming, for further discussion). However, there are two key issues regarding proffered interpretations in relation to parental stress and childhood disability. The first relates to ascribed causes of stress which are generally framed within a medical model discourse that views difficulties as necessarily emanating from the child's impairments, as opposed to social model interpretations which locate stressors as external to the child and family, such as lack of service support and negative social attitudes (Sloper 1999). This is by no means to minimise the often significant levels of stress and exhaustion experienced by families where children's needs are high and levels of support generally low, especially in relation to children with autism (see Hayes and Watson 2013). The second issue to foreground is that parenting experiences in families with disabled children are much wider than are generally portrayed. In a critical history of research on family responses to having children with disabilities, Ferguson (2002) argued that in recent years there has been some shift in focus towards exploring notions of family resilience and positive experiences. For example, Stainton and Besser (1998) discussed nine areas of benefit identified by fifteen parents of children with intellectual disabilities. More recently, in a meta-analysis of 17 qualitative studies, Griffith and Hastings (2014), found that parenting children with intellectual disabilities and challenging behavior encompassed a multitude of experiences, only some of which were stressful. Interestingly, they found that service provision, rather than supporting families, in many cases served to increase stress due to significant dissatisfaction with the provision offered.

While research on benefits flowing from the parenting of disabled children has begun to emerge, in the field of autism, Hastings et al. (2005) noted that such studies have generally been quantitative in nature, comparing levels of benefit finding between parents or investigating associations between benefit finding and other psychological characteristics such as adjustment (Samios, Pakenham, and Sofronoff 2009) or sense-making (Samios, Pakenham, and Sofronoff 2012). Regarding comparisons of benefit finding between parents, while mothers have often been reported as experiencing more stress than fathers of children with autism (Dabrowska and Pisula

2010; Tehee et al. 2009) they have also reported more positive parenting experiences (Kayfitz, Gragg, and Orr 2010; Samios, Pakenham, and Sofronoff 2009).

Fewer qualitative studies have been undertaken in relation to positive parenting experiences in the field of disability, although the importance of such narratives has been emphasized. Macartney (2010, 206) noted that:

“The unique position of family members presents an opportunity to explore, deconstruct and understand disability from “the inside”.

Fisher and Goodley explored the parenting experiences of 25 mothers of disabled babies and reported on the development of counter-narratives in which a “linear modernist medical narrative” (2007, 66) emphasising deficits and limited possibilities was resisted, with mothers focusing instead on the abilities of their children and their loving relationships with them.

In the field of autism although the need for more qualitative research has been acknowledged (Bolte 2014), relatively few such studies of parental experiences have been undertaken and even fewer which focus on the perspectives and experiences of fathers. MacDonald and Hastings (2010, 487) observe that the role of fathers of children with disabilities generally continues to be under-researched:

“..psychological research has typically focused on maternal and sibling functioning within families of children with developmental disabilities...where fathers have been included in the research, it is primarily to function as a contrast group to their female counterparts”.

Suggested reasons for this father-related omission include the predominance of methodological approaches which assume a model of maternal care and at a pragmatic level, that fathers are often viewed as a “hard to reach” group in research terms (MacDonald and Hastings 2010). Such rationales are likely to reflect an inherently deficit model of fatherhood which continues to be prevalent in psychological research. Such a stance reflects a “role inadequacy perspective” discussed by Hawkins and Dollahite which characterises fathering “as a social role

which men perform inadequately” (1997, 3), evidenced by an assumed lack of both paternal willingness and inability to nurture their children.

In the field of autism, there has been little exploration of the contribution fathers make to their children’s lived experiences or on the nature of the relationship between fathers and their children. In particular, research focusing on positive experiences of fathers of children with autism is especially rare.

The aim of this paper is to address this omission through an analysis of father reported benefits flowing from parenting their children with autism, by focusing on a portion of data from a broader study of father involvement in the lives of children with autism. Specifically, findings from an open-ended question in an online survey concerning perspectives on positive aspects of parenting are reported.

Methods

Ethical procedures

The research was given ethical approval by Leeds Beckett University. Fathers were given information concerning the aims of the research and were made aware that their responses would be anonymised and confidential in the introduction to the survey. Contact details for the researcher were provided should fathers have any questions and men were informed that should they continue to fill in the survey, it would be assumed that they had given their consent to take part. In an attempt to provide some direct benefit from participation, fathers were given the option of requesting a summary of findings in the survey itself and 80% (n=245) did so.

Participants and procedure

A convenience sample of fathers was recruited to an online survey which consisted of fathers (biological, adoptive, foster or step-fathers) of children with autism, autism spectrum disorder or Asperger’s Syndrome, aged up to 19 years and resident in the UK.

A range of mainly on-line recruitment strategies were used. A web link was e-mailed to over 80 local autism related voluntary groups and service providers in the UK three times over a period of five months who then forwarded it to their members or

clients. Web links to the survey were also provided on two national UK autism related websites during the same period. Further e-mails with a web link were sent to a number of autism specific schools and an advert was placed in an autism-related publication which is distributed nationally. Attempts to secure greater participation of fathers from black and minority ethnic backgrounds were made through collaboration with a major autism charity having links to community leaders.

Survey design

The survey, consisting of 52 closed and 5 open-ended questions, explored aspects of father involvement in the care, play and education. In keeping with Griffiths and Hasting's (2014) call to recognise and explore a wider range of parental experience in relation to childhood disability, father perceptions in the survey were explicitly sought in relation to both challenges and positive experiences. The more stressful aspects of their parenting role are discussed elsewhere (Potter, forthcoming).

Responses to the following open-ended question are reported here: "What kinds of things do you find satisfying about being the father of your child with autism?" and men were free to choose the length of their response.

Questions were developed through reference to the existing literature (see Towers [2009] for example) and the adaptation of items from relevant inventories, such as "The Inventory of Father Involvement" (Hawkins et al. 2002). There was also input from an expert verification group, consisting of a father of a child with autism, national consultants on autism and father inclusion, a leading academic in the field of family research and an expert in survey design and statistics.

Issues of bias, comprehensibility and social desirability in relation to item development were considered throughout. Initial drafts were first considered by the verification group and a pilot survey was then distributed to a group of fathers of children with autism who were asked to comment specifically on comprehensibility, length and relevance. Fathers reported the survey to be easily understood, was concerned with pertinent issues and did not take too long to complete.

Analysis

A conceptual descriptive approach was undertaken to data analysis. This is classified as “interpretive” according to a typology of qualitative findings developed by Sandelowski and Barroso (2003) who classified the nature of findings according to the degree of data transformation achieved. Distinctions are drawn according to the use of conceptual frameworks within analyses:

“In contrast to thematic surveys, in which authors often used concepts or themes from existing empirical or theoretical literature largely to organize the presentation of their findings, in conceptual/thematic descriptions, authors imported concepts or themes to reframe a phenomenon, event, or case” (2003, 913)

Here, at the first level, data was coded inductively for broad themes concerning the overall focus of responses, that is whether they referred exclusively to children’s qualities, impact of parenting on fathers or the relationships between fathers and children. A number of responses fell into more than one of these categories.

At the second level, analysis explored themes which emerged within these broader categories, such as the nature of children’s personal strengths identified and particular aspects of fathers’ personal development and role perception.

Representative quotations were then chosen from each second level theme to illustrate key themes. Finally, existing theoretical frameworks were introduced to position and reframe themes within wider disability and fatherhood discourses.

Research findings

Of the 306 fathers who completed the survey, 198 (65%) responded to the open-ended survey question under discussion and the vast majority of responses were positive in tone (96%). Most fathers responding to the question were white (95%), the child’s biological father (94%) and were aged 40 or above (79%). Most men were fathers of one child with autism, (87%) while 10% of fathers had two children on the autism spectrum. The majority of men were in a couple relationship, living with the child’s mother (90%) and just over half were educated to degree level or above (57%). A majority of fathers completing the question were employed full-time (61%)

and 11% were retired or not in employment and 40% of men lived in the south of England (London, the South West or the South East).

Some fathers answered the question concerning positive aspects very briefly, while others wrote more extensively. Frequently the shortest responses were particularly striking: “love”. Longer responses explored a wider range of issues, sometimes including reference to challenges as well as positive experiences.

Focus on children

Children: not children with autism

Thirteen fathers explicitly sought to reject deficit narratives in relation to their children in forthright and powerful ways:

The autism is irrelevant.

I love him for who he is. He is my child and he happens to have autism.

It's not the autism, it is just that he is my lad,

These succinct but striking comments resonate with Gray's, (2001) reported narratives of “resistance” in which parents of children with autism challenged “professionally based ideologies of adjustment and adaptation” (p. 1256) in favour of “personal assertiveness”. Further, such statements echo results from Dorozenko, Roberts, and Bishop's (2015) study in which staff working with adults with intellectual disability framed individuals identities in terms of agency and ability rather than deficit and incompetence.

Some fathers compared their parenting role to that of other fathers of children without autism, emphasising similarity rather than difference:

All the good things of being a father. All the good things of relating to him as a specific individual. Not sure anything specifically because he has ASD.

I accept my son for who he is. To that end he has incredible character and personality and surprises me frequently with the things that he can do that perhaps I didn't expect him to be able to do.

Again, such perspectives reject the “othering” of their children as did mothers of disabled babies in Fisher's (2007) study who believed that their children's differences should be constructed not as “problems” or “abnormalities” but rather as an expression of human diversity which should be valued.

Children's personal strengths

Another major theme to emerge related to fathers valuing positive characteristics of their children with autism, with half of men commenting on this aspect. Fathers highlighted a range of their children's personal qualities which they found especially valuable.

Interpersonal abilities

In the light of the almost exclusive emphasis in the literature on the deficits of children with autism in the area of interpersonal skills, it is significant that a number of fathers commented on their children's social strengths:

He is extraordinary - funny, clever, caring. It is a privilege to be his dad.

He can be incredibly perceptive and sensitive.

He is the most gentle and loving child.

He is the sweetest kindest most loyal person I have ever known.

Whilst behaviour can be very challenging, he can have very caring moments at times which is good to see.

Honesty

Honesty was another quality which nine fathers found particularly attractive in their children:

The direct honesty of everything from her affection to her attitudes.

The honesty and clarity with which he sees the world. It's refreshing.

Having a child who is honest, who has no "hidden agendas".

He never lies and...tells us/ people how he sees things

Inability to deceive has generally been portrayed in medical model terms. For example, Ranick et al. (2013, 503) noted: “previous research has shown that

children with autism often have deficits in deception". Such an inability is compared negatively to the ability of the "average person" who has been estimated to tell one to two lies per day. From a social model perspective, an inability to lie becomes an impairment in a world where most others deceive.

Sense of humour

Fourteen fathers highlighted their children's sense of humour as a valued quality:

Great sense of humour

His sense of humour shines through.

He loves to laugh with us

His sense of humour is fantastic

This focus on humour as a particular strength is illuminating. From developmental and psychological perspectives, possession of a sense of humour has been seen as important in developing interpersonal relationships (Curry and Dunbar 2013), fostering intimacy (Martin 2002), contributing to mental health (Samson and Antonelli 2013) and developing self-esteem (Dyck and Holtzman 2013). This characteristic has often been identified as extremely limited or lacking within children with autism (Wu et al. 2014). The ways in which fathers and mothers share humour with their children with autism may be an important avenue for future research, since such a process seems an important aspect of both personal and interpersonal development.

Intellectual abilities

Thirteen fathers commented on their children's intellectual abilities and fathers who were educated to degree level or above were more likely to do so.

He is an independent and abstract thinker. He is a problem solver

My son has an exploring mind

His intelligence, he remembers a lot of stuff

He's wonderful - charming, intelligent, witty etc.

Some fathers whose children who had limited use of language commented on pleasure in seeing progress:

Every little, tiny achievement my son makes is a thrill

Small improvements become big events!

Just enjoy all the times my child copes with a situation that you thought he would struggle in

The cognitive abilities of some individuals with autism have been often been commented on in the literature, through use of such terms as “savant”. For example, Dubischar-Krivec et al. (2014, 157) observed:

“The savant-syndrome is a phenomenon of intellectual or sensory dysfunction paired with an outstanding capacity in a circumscribed domain of cognitive or artistic function”.

It is interesting to note that in relation to people with autism, even “outstanding capacity” is conceptualised in deficit terms. In addition, the intellectual ability or progress of children with autism with additional learning disabilities receives scant attention in the literature, again contributing to almost exclusively deficit model narratives (Petrina et al. 2014).

These statements focusing on children’s positive personal qualities are both powerful and challenging. Children are presented as capable (he is a problem solver) dynamic (his never ending energy), persistent (he is undaunted by most hurdles) as well as personable (charming; pleasant) and emotionally supportive (loyal; sensitive; kind). Such positive, capacity-orientated perspectives on the qualities and abilities of children on the autism spectrum rarely appear in the literature, in a field dominated by quantitative, deficit model research. Indeed, it has been noted that when parents do articulate more positive perspectives, they may be characterised as denying the reality of their situation and the necessarily negative implications of their children’s impairments. (Ryan and Runswick-Cole 2008).

Renshaw, Choo, and Emerald's (2014) analysis of how “diverse disability identities” are “accomplished” for two disabled children in special education settings by their parents and teachers, is instructive here. They argued that the predominance of a medical model discourse ensured that children’s “everyday lives are constructed

through narratives of concern, care and specialised treatment” and that the result of such accounts is that children with disabilities are “typically constructed as acted upon, rather than acting” (2014, 47). Such a focus on disability as the identity category, it is argued “can mask the complexity of individual identities and capabilities among children with a disability” (2014, 47). Many fathers in this study sought to construct their children’s identities in opposition to a deficit orientated discourse, emphasising instead children’s abilities, strengths and agency. Hanisch in his review of four Scandinavian anthologies of narratives by parents of disabled children, published between 1996–2008, reflected on one important aspect of collections, namely “Stories of appreciation”, noting that

“Telling stories that value the child in its ‘alterity’ and ‘particularity’ can be enabling perhaps even on a more fundamental level than politicised narratives...” (2013, 1156).

Father-Child relationships

Thirty nine fathers responding to the question focused on aspects of the relationship between themselves and their children with autism in responding to the question under discussion, with a frequent emphasis on “love” and loving relationships:

I have learnt what love really is

He’s my son I love him what could be more satisfying than see him grow into the really nice decent person he is.

Sixteen fathers referred to the satisfying levels of affection which their children with autism displayed towards them:

Getting affectionate responses.

When my son hugs me and says "I love you“.

The cuddles I get back and the jokes we tell one another.

He is so loving.

One non-resident father talked about his creation of a stable environment which had enabled the development of loving relationships with his children with autism:

As a non-resident Dad, it's how far we've come, developing our relationship from near-zero to where we are. We now have a home together, with our own routines based on their Mum's. We do lots together, and there's a lot of love here.

Fathers also talked about the strong emotional bond they experienced with their children, sometimes comparing this to what they observed in fathers of typically developing children.

When your child tells you he loves you after nearly 7 years because he has realised what this means, that is the most satisfying and rewarding moment in being a father.

As a father and son, I feel that our relationship is closer than in other families. He relies on my support and understanding and never holds back on his needs or feelings.

Ten fathers explicitly valued what they could share with their children

When we find common ground/interest, it is very satisfying as he will give full attention to this.

We are able to share his special interests and spend time doing things and talking about things that he is passionate about. I feel very needed and important in my son's life.

These powerful comments focusing on the strength of fathers' relationships with their children with autism and the ability of children to engage in loving relationships constitute some of the most important findings in this study. In their emphasis on love, bonds, affection and sharing, fathers comments directly challenge dominant deficit model discourses which emphasize the inability of children with autism to make meaningful relationships. The vast majority of studies in the field typically begin with a list of individual deficits in areas of social and emotional development, such as:

"Individuals with autism spectrum disorders (ASDs) experience significant difficulties in social functioning, including deficits in core social abilities and

problems establishing and maintaining peer relationships (Mazurek, 2013, p.223).

While individuals with autism do experience a range of challenges in their social interactions, sometimes due to the nature of disabling communication environments (see XXX and XXX, X), the strengths-based narratives of fathers reported here indicate that the social and emotional experiences of individuals with autism and their families are more complex, nuanced and positive than deficit model studies suggest.

Focus on fathering

Valuing the nurturing role

Nearly 30% of fathers (n=57) responded to the question under discussion by commenting generally on the satisfaction they experienced as a result of their fathering role. Men referred to the value which they placed on nurturing aspects of their relationship with their children. “Being there” for children was a recurring sentiment, closely related to notions of offering support and love.

I know I'm always there for him...

Being there for her unconditionally...

Several fathers spoke of the ways in which they had made a positive difference to their children’s lives, both in terms of their ability to enjoy their lives and with regard to personal development:

When you feel you have made a difference...

Being able to help him develop as a young adult

Enabling him to progress. Enabling him to have fun

I think it's that I get to spend so much time with my kids and I get to have a massive influence in their education.

Some fathers highlighted the strong connection between their children’s well-being and their own:

When a child with autism smiles they REALLY mean it there is no faking. I love to make them smile. It gives my life a real reason.

In longer responses, some fathers expressed the range and complexity of their role in their children's lives, emphasizing affective aspects of shared lives and mutually satisfying relationships:

I cherish being the one he comes to when he wants help and wish he would do this more. I love being there for him and wish I could do more. I love the activities we do together and the trips we take. I love his enthusiasm and knowledge about his areas of special interest. I love him.

These strong statements challenge notions of fatherhood which often remain negative and undermining. In a thematic review of 12 sitcoms featuring father characters, Pehlke II et al. (2009) found that while these characters displayed some more positive parenting traits, nevertheless, comedic aspects of the dramas often related to portrayals of paternal incompetence or "buffoonery". Hawkins and Dollahite (1997) strongly disputed deficit representation of men's parenting capabilities and practices, arguing instead for a generative model or "fatherwork" approach which roots fathering in notions of care and ethical endeavour.

Personal development

Nine fathers reflected on the ways in which they had developed personally as a result of parenting their child with autism, often in relation to an increased ability to be tolerant and compassionate:

We have changed and developed as people as a result of our involvement with our daughter and the challenges that we have faced together. She is ... a joy to us now.

I feel that my son has made me much more tolerant person having to work hard with him has brought me closer to him and made me realise what a beautiful and precious child I have.

I have learned a lot about tolerance and patience. I can see the results of my work with my son

One father expressed the sometimes complex emotional process of parenting his son with autism in a brief but extremely powerful statement:

It demands that I'm a better person, and the edge of pain that goes with the love makes the tenderness I feel towards my son overwhelming at times

Two fathers commented on the child's own role in the father's learning:

He teaches me new things every day

We are sharing an educational journey

Fisher and Goodley (2007) noted the need to avoid positioning such personal development narratives within a deficit model interpretation where children's impairments again become the focus, not in the more usual sense where they necessarily lead to stressful experiences but in terms of impairments being so great a challenge as to necessarily demand unusual levels of response from parents. Instead, they argued the positive narratives of mothers concerning their disabled babies could in fact be interpreted as evidence that they are "simply subscribing to normative notions of good mothering" (2007, 75). Similarly, McDonnell et al. (2015) argued that the experience of parenting disabled children, as with that of non-disabled children may be "transformational" and one through which all parents necessarily make accommodations and find benefits.

Diversity of father experience

Fathers of children with autism do not comprise a monolithic group and the backgrounds of fathers responding to the survey differed in ways which may have affected their parenting experiences in general and their views on positive perspectives in particular. For example, fathers of children educated to degree level or above were more likely to comment on the intellectual capacities of their children in response to the question under discussion here. In addition, there were some differences in tone depending on children's ability levels. While many fathers having children with autism and additional disabilities made a range of positive comments, nine fathers of children with autism, learning disabilities and challenging behaviour were unable to do so:

I hate the fact that my little boy is autistic.

I don't actually see any positives or good points about having a child with autism. I think we are dealing with it the best we can, but that's it.

Such findings align with those of other studies where families of children with intellectual disability and challenging behaviour have identified fewer positive perceptions than others (see Horsley and Oliver [2015] for a meta-analysis). It is important to note, however, that most fathers expressing negative responses here reported inadequate support and service provision in other parts of the survey which may serve to contextualise these views to some extent. Indeed, the association between parental stress and inadequate social and economic support has been well documented in the field (see for example Falk, Norris, & Quinn, [2014]).

There were twenty six question responses from fathers having more than one child with autism, twenty five of which were positive. Two comments were:

I think that my children with all their special needs...have to work so hard to be accepted by our society but I feel honoured to be bringing up my children and amazed at how they cope with their difficulties.

Loving them for who they are. Finding some of the unusual things they find funny that other children might not. How good they are on car journeys!

Research exploring the experiences of families having more than one child with autism is scarce, with studies exploring father perspectives even more infrequent. In a rare qualitative study, Waterson (2012) reported on generally high levels of coping and resilience in eleven such families, alongside parental narratives which challenged tragedy model perspectives. Clearly more research is needed which focuses on how diversity of parental experience may affect dynamics and relationships in families having children with autism.

Discussion

The findings presented here add to our understanding of the positive parenting experiences of fathers of children with autism. Key thematic areas were identified as children's strengths and personal qualities, loving and rewarding relationships with children, satisfaction with aspects of their fathering role and an awareness of personal development.

The extent to which many fathers highlighted their children's strengths and positive personal qualities was noteworthy. Such strengths-based commentaries are rare in a field which is dominated by deficit model research and discourse and are illuminating in a number of important ways. First, fathers' emphasis on capacity identifies their children with autism as capable of active agency and achievement within the context of their own lives and within their wider family relationships. There are resonances here with the findings of Fisher and Goodley (2007) who refer to the counter-narratives of mothers of disabled babies who through valuing their children's uniqueness and difference were able to "embrace alternative and positive frameworks of meaning" (p.76). The strengths based perspective adopted by fathers here can be seen as relevant in relation to the recently proposed "disabled children's childhood studies" articulated by Curran and Runswick-Cole (2014) who argued that the perspectives and lived experiences of disabled children are not sufficiently taken account of by either the field of disability studies or childhood studies. Within the context of the new sociology of childhood, they maintained that disabled children are generally viewed as a special case, thereby contributing to, rather than arguing against discourses which "other" the experience of their childhoods. They argued that a new "disabled children's childhood studies" is needed that views disabled children as influential, agential decision-makers rather than vulnerable children existing on the edge of a childhood studies discourse (Curran and Runswick-Cole 2014). Fathers' representations here of children with autism as purposeful, animated, creative and persistent, speaks to such a capacity orientated perspective which challenges a range of deficit based assumptions about their children's current and future potential.

There are implications for service provision. While it is the case that encounters between professionals and parents of disabled children necessarily occur as a result

of a diagnosis of impairment, such interactions form important spaces where children's identities may be "accomplished" and the prevalence of deficit-only narratives risk two serious repercussions. First, such interactions may deleteriously influence parents' own ways of seeing their children, since as Goddard et al. (2000, 284) discussed parental perspectives are developed in complex ways and "the risk is that those differences [foregrounded by their child's diagnoses] come to stand for an individual's identity". Indeed, Scorgie et al. (2001) found that the valuing of children's strengths and contribution to family life was extremely important for parents of children with Down's Syndrome in achieving a more positive quality of life. Furthermore, service narratives which focus only on impairment and challenge are likely to undermine the vital relationship between parents and professionals. Fisher and Goodley (2007, 78) reported that professionals who were found to be most supportive by mothers of disabled babies were those who "acknowledge the children's humanity and the fact that the children have much to offer in relationships of great mutual value".

Fathers' powerful comments of the rewarding nature of their relationships with their children with autism constitute another key theme in this study. Deficits in the area of interpersonal interaction and forming relationships with others have formed the basis of the diagnosis of autism over a seventy year period. Very little research within the mainstream autism literature has focused on the social strengths of individuals which may relate in part to epistemological issues. In an editorial of a major autism journal, Bolte (2014, 68) observed: "The number of original studies that use qualitative methods in respected peer-reviewed journals is negligible compared to quantitative ones". Such a position, itself, appears explanatory in terms of the scarcity of studies exploring the social capabilities of individuals with autism since a qualitative approach is needed to understand the complex and multifaceted aspects of the nature of interpersonal relationships. Father observations here on features of their children's social abilities have emerged from years of intimate everyday interactions and greater research focus on the narratives of mothers and fathers has the potential to widen and deepen our understanding of the capabilities of individuals with autism, within enabling family contexts. Potter and Whittaker (2001, 13) argued for the use of a capacity perspective when working with children with autism and additional

intellectual disabilities on facilitating social abilities, stating that a focus only on impairments may

“result in a range of inappropriate beliefs about the potential of these [children] which in turn may adversely affect their prospects for a good quality of life”.

A further finding relates to the nurturing role of fathers in the lives of their children with autism. Little is known about the ways in which fathers influence and contribute to the lives of their children with autism or on the nature of the relationships they experience with them, with a few notable exceptions, including those relating to father involvement in the play and leisure of children on the autism spectrum, for example (see Mitchell and Lascwicz [2015]; Potter, in press). In this study, many fathers chose to focus on the caring aspects of their parenting roles, with many references to “love”, “care” and “sharing”. Some fathers expressed strong attachment to their children in powerful emotional terms, often referring to aspects of the emotional labour involved in the development of these relationships. Such narratives resonate with findings from the small number of other qualitative studies studies in the field where fathers have been found to experience intense and dedicated relationships with their children with autism (see Keller, Ramisch, and Carolan, [2014] and Meadan, Stoner, and Angell, [2015] for example). In the field of learning disabilities, a key theme to emerge from Boström and Broberg, (2014)’s longitudinal study of seven Swedish fathers of children with intellectual disabilities was the importance men attached to being a “good father”. Similarly Towers (2006) discussed the high levels of paternal involvement in the day to day care of their children with intellectual disabilities and the centrality of this role in their lives.

The perspectives of fathers presented here speak to the generative abilities of these fathers, in their explicit valuing of the “fatherwork” they have undertaken with their children. This study highlights the extent to which fathers are emotionally involved with their children while at the same time research continues to find that fathers often remain “the invisible parent” (West 2000) in terms of service inclusion. Flippin and Crais (2011) found that fathers of children with autism were rarely considered in relation to research or service provision while in a UK survey Scourfield et al. (2014) concluded that the number of men receiving family services was “typically small” (p.47). Ryan and Runswick-Cole (2008) persuasively argued for a repositioning of mothers within the disability literature, through a more holistic exploration of the ways

in which all family members, particularly fathers, experience aspects of disablism. It is argued here that fathers of disabled children are not so much in need of repositioning, so much as recognising, as highlighted by Towers (2009) in her survey study of fathers of children with intellectual disabilities. Greater exploration of the experiences of fathers of children with disabilities would further illuminate aspects of a key family relationship which has often been overlooked in the past. Such increased knowledge translated into enhanced provision which includes fathers is likely to improve the quality of life for whole families since as Doherty, Kouneski, and Erickson (1998, 227) argued, the welfare of fathers, mothers, and children are “intertwined and interdependent”. Furthermore, as Keller, Ramisch, and Carolan (2014) highlighted, it will be important to explore the diversity of father characteristics and experience in relation to the development of positive relationships with their children with autism since, as we have seen here, a number of factors may impact this significant process.

It is important to stress that the findings presented here relating to positive father experiences in no way seek to detract from or deny the many significant challenges which mothers and fathers of children with autism frequently experience within their parenting roles. As discussed earlier, the causes of such stress are likely to be complex, very often relating to inadequate or inappropriate service provision from diagnosis onwards (Crane et al. 2015; Pellicano, Dinsmore, and Charman 2014). What is argued is that overwhelmingly deficit-orientated narratives do not capture the full range of parental experiences and may themselves contribute significantly to family difficulties. Additional qualitative research is therefore needed which foregrounds both maternal and paternal narratives concerning the full range of their parenting experiences, including those which are positive. Further work is needed on how service interventions may better incorporate such perspectives, particularly during the early days following diagnosis where professional narratives may be especially bleak (Potter, forthcoming)

Although the current study introduces a number of innovative findings, there are several limitations to be noted. First, it reports only on father perspectives. A father-only study was designed deliberately since the use of gender-blind recruitment has typically resulted in low numbers of father responses leading to a significant under-

representation of father perspectives in the autism literature (Braunstein et al. 2013) and more widely in the field of intellectual disability. Furthermore, the views of fathers who did not respond to this open-ended question may have been less positive. In addition, men from black and minority ethnic backgrounds are under-represented. Ferguson (2002) argued that since both family and disability are culturally constructed, the ways in which mothers and fathers from differing cultural backgrounds experience and make sense of disability will vary considerably. Waheed et al. (2015) identified 33 barriers to recruiting participants from ethnic minority groups to mental health research studies which they categorised in relation to five themes, namely: participant related barriers; practical issues; family/community related; health service related and research process related. They subsequently developed a typology of recruitment strategies aimed at overcoming these specific barriers, including for example, the planning of outreach activities in target communities and engaging the services of a “culturally competent” insider to facilitate access. Such culturally specific and sensitive strategies should be employed in future research to gain greater participation of mothers and fathers from black and minority ethnic backgrounds. In addition, the analysis of responses to open-ended survey questions presents methodological challenges to researchers in terms of analysis, since as Jackson and Tochim (2002) note, their relative brevity can remove views and experiences from their wider context. However, as the direct quotations reported in this paper illustrate, such data can be extremely rich as a result of having been distilled, reflecting sometimes powerful observations or emotion. Secondly, the analysis of such open-ended survey questions gives voice to larger numbers of participants, especially salient here for fathers whose voices are rarely heard in both the disability and wider literature. Finally, the fact that fathers completing the survey were self-selecting and mostly recruited through organisations likely to project affirmative perspectives on autism may have predisposed them to offer positive perspectives themselves.

Conclusion

This study extends our understanding of the ways in which fathers of children with autism perceive their positive parenting experiences. There was a strong focus on children’s personal strengths and the presence of strong emotional bonds within

father-child relationships. Fathers valued their own nurturing roles and reflected on aspects of personal development in sometimes powerful ways. It is argued that a greater focus on positive aspects of the experiences of parents of children with autism, through qualitative methodologies would serve to broaden and deepen our understanding of important aspects of family life. Such a focus would also serve to foreground the active agency of children with autism within their family contexts which has received little attention within a field where deficit representations prevail. These more complex perspectives should inform service provision. Professional narratives are needed which explicitly value children with autism as individuals with a range of personal strengths and abilities, rather than those which unconsciously may serve to objectify children through a focus on deficits which imply that children's identities amount to little more than the product of their impairments.

References

- Allen, K., A., Bowles, T., V., and Weber, L., L. 2013. "Mothers' and Fathers' Stress Associated with Parenting a Child with Autism Spectrum Disorder". *Autism Insights* (5): 1–11.
- Bölte, S. (2014). "The power of words: Is qualitative research as important as quantitative research in the study of autism?" *Autism*, 18(2): 67–68.
- Boström, P. K., and Broberg, M. 2014. "Openness and avoidance: a longitudinal study of fathers of children with intellectual disability". *Journal of Intellectual Disability Research* 58(9): 810–821 12p. <http://doi.org/10.1111/jir.12093>
- Braunstein, V. L., Peniston, N., Perelman, A., and Cassano, M. C. 2013. "The inclusion of fathers in investigations of autistic spectrum disorders". *Research in Autism Spectrum Disorders* 7(7): 858–865.
- Casey, L. B., Zanksas, S., Meindl, J. N., Parra, G. R., Cogdal, P., and Powell, K. 2012. "Parental symptoms of posttraumatic stress following a child's diagnosis of autism spectrum disorder: A pilot study". *Research in Autism Spectrum Disorders* 6: 1186–1193.
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., and Hill, E. 2015. "Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom". *Autism: The International Journal of Research and Practice*. (on-line earlyRetrieved from <http://ezproxy.leedsbeckett.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cmedmandAN=25810370&site=eds-live&scope=site>
- Curran, T., and Runswick-Cole, K. 2014. "Disabled children's childhood studies: a distinct approach?" *Disability and Society*, 29(10): 1617.
- Curry, O. S., and Dunbar, R. I. M. 2013. "Sharing a joke: The effects of a similar sense of humor on affiliation and altruism". *Evolution and Human Behavior* 34: 125–129.
- Dabrowska, A., and Pisula, E. 2010. "Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome". *Journal of Intellectual Disability Research* 54(3): 266–280.

- Doherty, W. J., Kouneski, E. F., and Erickson, M. F. 1998. "Responsible Fathering: An Overview and Conceptual Framework". *Journal of Marriage and Family* 60(2): 277–292.
- Dorozenko, K. P., Roberts, L. D., and Bishop, B. 2015. "The identities and social roles of people with an intellectual disability: challenging dominant cultural worldviews, values and mythologies". *Disability and Society* 30(9): 1345–1364.
- Dyck, K. T. H., and Holtzman, S. 2013. "Understanding humor styles and well-being: The importance of social relationships and gender". *Personality and Individual Differences* 55: 53–58.
- Ferguson, P. M. 2002. "A Place in the Family: An Historical Interpretation of Research on Parental Reactions to Having a Child with a Disability". *Journal of Special Education* 36(3): 124-130.
- Fisher, P. 2007. "Experiential knowledge challenges "normality" and individualized citizenship: Towards "another way of being." *Disability and Society* 22(3): 283–298.
- Fisher, P., and Goodley, D. 2007. "The linear medical model of disability: Mothers of disabled babies resist with counter-narratives". *Sociology of Health and Illness* 29(1): 66–81.
- Flippin, M., and Crais, E. R. 2011. "The Need for More Effective Father Involvement in Early Autism Intervention". *Journal of Early Intervention* 33(1), 24–50.
- Goddard, J. A., Lehr, R., and Lapadat, J. C. 2000. "Parents of Children with Disabilities: Telling a Different Story". *Canadian Journal of Counselling* 34(4): 273–89.
- Gray, D. E. 2001. "Accommodation, Resistance and Transcendence: Three Narratives of Autism". *Social Science and Medicine* 53: 1247–1257.
- Griffith, G. M., and Hastings, R. P. 2014. "'He's hard work, but he's worth it'. The Experience of Caregivers of Individuals with Intellectual Disabilities and Challenging Behaviour: A Meta-Synthesis of Qualitative Research". *Journal of Applied Research in Intellectual Disabilities* 27(5): 401–419.
- Hanisch, H. 2013. "Politics of Love: Narrative Structures, Intertextuality and Social Agency in the Narratives of Parents with Disabled Children. *Sociology of Health and Illness* 35(8): 1149.

- Hartley, S. L., Seltzer, M. M., Head, L., and Abbeduto, L. 2012. "Psychological Well-being in Fathers of Adolescents and Young Adults with Down Syndrome, Fragile X Syndrome, and Autism". *Family Relations* 61(2): 327–342.
- Hastings, R. P., Kovshoff, H., Ward, N. J., degli Espinosa, F., Brown, T., and Remington, B. 2005. "Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism". *Journal of Autism and Developmental Disorders* 35(5): 635–44.
- Hawkins, A. J., Bradford, K. P., Palkovitz, R., Christiansen, S. L., Day, R. D., and Call, V. R. A. 2002. "The Inventory of Father Involvement: A Pilot Study of a New Measure of Father Involvement". *Journal of Men's Studies* 10(2): 183–196.
- Hawkins, A. J., and Dollahite, D. C. 1997. *Generative Fathering: Beyond Deficit Perspectives*. Thousand Oaks, CA: Sage.
- Hayes, S., and Watson, S. 2013. "The Impact of Parenting Stress: A Meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children with and without Autism Spectrum Disorder". *Journal of Autism and Developmental Disorders* 43(3): 629–642.
- Horsley, S., and Oliver, C. 2015. "Positive impact and its relationship to well-being in parents of children with intellectual disability: a literature review". *International Journal of Developmental Disabilities* 61(1): 1–19.
- Jackson, K. M. and Trochim, W. M. K. 2007. Concept Mapping as an Alternative Approach for the Analysis of Open-Ended Survey Responses *Organizational Research Methods* 5(4): 307-336.
- Kayfitz, A. D., Gragg, M. N., and Orr, R. R. 2010. "Positive Experiences of Mothers and Fathers of Children with Autism". *Journal of Applied Research in Intellectual Disabilities* 23: 337–343.
- Keller, T., Ramisch, J., and Carolan, M. 2014. "Relationships of Children with Autism Spectrum Disorders and their Fathers". *Qualitative Report* 19(33): 1-15.
- Kiani, F., khodabakhsh, M., Reza, and Hashjin, H., Khastwo. 2014. "A Comparison Study about Association of Stress and Depression in Children's Mothers with and without Autism Spectrum Disorders (ASD)". *International Journal of Pediatrics (2345-5047)* 2(3.3): 31–37.

- Lalvani, P., and Douglas, L. P. 2013. "Historical Perspectives on Studying Families of Children with Disabilities: A Case for Critical Research". *Disability Studies Quarterly* 33(3), 9. <http://dsq-ds.org/article/view/3209/3291>).
- Macartney, B. 2010. "Living on the Edge of the Normal Curve: 'It's Like a Smack in the Head.'" In C. Dudley-Marling and A. Gurn (Eds.), *The Myth of the Normal Curve*. New York: Peter Lang Publishing.
- MacDonald, E., and Hastings, R. 2010. "Mindful Parenting and Care Involvement of Fathers of Children with Intellectual Disabilities". *Journal of Child and Family Studies* 19: 236–240.
- Martin, R. A. 2002. *The Psychology of Humor: An Integrative Approach*. Academic Press.
- Mazurek, M. O. 2013. "Loneliness, friendship, and well-being in adults with autism spectrum disorders". *Autism: The International Journal of Research and Practice* 18(3): 223–232
- McConnell, D., Savage, A., Sobsey, D., and Uditsky, B. 2014. "Benefit-finding or finding benefits? The positive impact of having a disabled child". *Disability and Society* 30(1): 29–45.
- Meadan, H., Ostrosky, M. M., Zaghlawan, H. Y., & Yu, S. 2009. "Promoting the Social and Communicative Behavior of Young Children with Autism Spectrum Disorders: A Review of Parent-Implemented Intervention Studies". *Topics in Early Childhood Special Education* 29(2): 90–104.
- Mitchell, J., and Lashewicz, B. 2015. "More Than a Pal: The Generative Leisure Work of Fathers Raising Children with Autism Spectrum Disorder". *Fathering* 13(2): 130–145.
- Pehlke II, T., Hennon, C. B., Radina, M. E., and Kuvalanka, K. A. 2009. "Does Father Still Know Best? An Inductive Thematic Analysis of Popular TV Sitcoms". *Fathering: A Journal of Theory, Research, and Practice about Men as Fathers* 7(2): 114–139.
- Pellicano, E., Dinsmore, A., and Charman, T. 2014. "What should autism research focus upon? Community views and priorities from the United Kingdom". *Autism: The International Journal of Research and Practice* 18(7): 756.

- Petrina, Neysha, Carter, M., and Stephenson, J. 2014. "The nature of friendship in children with autism spectrum disorders: A systematic review". *Research in Autism Spectrum Disorders* 8(2): 111–126.
- Pisula, E., and Kossakowska, Z. 2010. "Sense of coherence and coping with stress among mothers and fathers of children with autism". *Journal of Autism and Developmental Disorders* 40(12): 1485–94.
- Potter, C. A. (Forthcoming) *Fathers of Children with Autism: Experiences, Practices and Service Use*. London: Routledge.
- Potter, C. A. (in press) Father Involvement in the Care, Play and Education of Children with Autism. *Journal of Intellectual and Developmental Disability*
- Potter, C. A. 2015. "“I didn’t used to have much friends”": Exploring the Friendship Concepts and Capabilities of a Boy with Autism and Severe Learning Disabilities". *British Journal of Learning Disabilities* 43(3): 208–218.
- Potter, C. A., and Whittaker, C. 2001. *Enabling Communication in Children with Autism*. London: Jessica Kingsley Publishers.
- Ranick, J., Persicke, A., Tarbox, J., and Kornack, J. A. 2013. "Teaching Children with Autism to Detect and Respond to Deceptive Statements". *Research in Autism Spectrum Disorders* 7(4): 503–508.
- Renshaw, P., Choo, J., and Emerald, E. 2014. "Diverse disability identities: The accomplishment of “Child with a disability” in everyday interaction between parents and teachers". *International Journal of Educational Research* 63: 47–58.
- Ryan, S., and Runswick-Cole, K. 2008. "Repositioning Mothers: Mothers, Disabled Children and Disability Studies". *Disability and Society* 23(3): 199–210.
- Samios, C., Pakenham, K. I., and Sofronoff, K. 2012. "Sense making and benefit finding in couples who have a child with Asperger syndrome: An application of the Actor-Partner Interdependence Model". *Autism* 16(3): 275–292.
- Samios, C., Pakenham, K. I., and Sofronoff, K. 2009. "The nature of benefit finding in parents of a child with Asperger syndrome". *Research in Autism Spectrum Disorders* 3(2): 358–374.
- Samson, A. C., and Antonelli, Y. 2013. "Humor as character strength and its relation to life satisfaction and happiness in Autism Spectrum Disorders". *Humor: International Journal of Humor Research* 26(3): 477–491.

- Sandelowski, M., and Barroso, J. 2003. "Classifying the Findings in Qualitative Studies". *Qualitative Health Research* 13(7): 905–923
- Scorgie, K., Wilgosh, L., Sobsey, D., and McDonald, J. 2001. "Parent Life Management and Transformational Outcomes when a child has Down Syndrome". *International Journal of Special Education* 16: 57–68.
- Scourfield, J, Cheung, SY and Macdonald, G. 2014. "Working with fathers to improve children's well-being: Results of a survey exploring service provision and intervention approach in the UK". *Children and Youth Services Review* 43: 40-50.
- Sloper, P. 1999."Models of service support for parents of disabled children. What do we know? What do we need to know?" *Child: Care, Health and Development* 25(2): 85–99.
- Stainton T, and Besser, H. 1998. "The positive impact of children with an intellectual disability on the family". *Journal of Intellectual and Developmental Disability* 23(1): 57–70.
- Tehee, E., Honan, R., and Hevey, D. 2009. "Factors Contributing to Stress in Parents of Individuals with Autistic Spectrum Disorders". *Journal of Applied Research in Intellectual Disabilities* 22(1): 34–42.
- Towers, C. 2009. *Recognising Fathers: A National Survey of Fathers who have Children with Learning Disabilities*. Foundation for People with Learning Disabilities.
- Towers, C. 2006. "*Recognising Fathers. Understanding the issues faced by fathers of children with a learning disability*". London: Mental Health Foundation.
- Waheed, W., Hughes-Morley, A., Woodham, A., Allen, G., and Bower, P. 2015. "Overcoming barriers to recruiting ethnic minorities to mental health research: a typology of recruitment strategies". *BMC Psychiatry* 15(1): 101–111.
- Waterson, I. 2012. "The Coping Strategies of Families who have more than One Child with Autism : A Qualitative Study". (Doctoral dissertation). Retrieved from <http://ezproxy.leedsbeckett.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edsble&AN=edsble.572064&site=eds-live&scope=site>
- West, S. 2000. "*Just a Shadow: A Review of Support for the Fathers of Children with Disabilities*". Birmingham: The Handsel Trust.

Wu, C.-L., Tseng, L.-P., An, C.-P., Chen, H.-C., Chan, Y.-C., Shih, C.-I., and Zhuo, S.-L. 2014. "Do individuals with autism lack a sense of humor? A study of humor comprehension, appreciation, and styles among high school students with autism". *Research in Autism Spectrum Disorders* 8 (1): 1386-1393.