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Support Needs of Fathers of Children with ASD: Individual, Family, Community and Ideological Influences

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Introduction Fathers are increasingly involved in caring for children, and involvement by fathers of children with ASD is distinctly impacted by added demands of their child's diagnosis. Yet supports for families of children with ASD are not tailored to needs of fathers. We use an ecological framework to examine how fathers' needs are influenced by contexts ranging from the immediacy of their child's behaviour to overarching expectations for good fathering.
Methods We thematically analyse data from semi-structured interviews with 28 fathers of children with ASD who shared parenting stories of navigating their immediate and broader environments.
Findings Fathers are responsive and reflective in their parenting and value recreationally based support activities that include their children. Fathers endorse father-to-father support and are interested in mentoring fathers newer to the experience of having a child with ASD.
Conclusions Fathers are resourceful parents who compel a critical re-examination towards advances in father-friendly practices.

Keywords: autism spectrum disorders, family studies, fathering, support needs

Background

Fatherhood is typically socially constructed as well as biologically acquired; thus, its particular significance is subject to social, economic and political influences across time (Morman & Floyd 2002). For the majority of the 20th century, fathers were in the background of active parenting as their primary responsibilities centred on generating income outside the home. Lamb (2000) claims that understandings of fatherhood have always been multifaceted, shifting through stages across history. Father roles have evolved through emphases on moral guidance, breadwinning, sex-role modelling, marital support and, finally, nurturance (Lamb). Before the industrial revolution, fathers assumed responsibility for teaching their children values and spearheading education. After the industrial revolution, fatherhood underwent a shift such that fathers were encouraged to define themselves as breadwinners, the primary providers for their family's financial needs. This definition prevailed until after the great depression when fathers' moral guidance and breadwinning remained important yet fathers in the 1930–1940s were increasingly expected to be strong sex-role models, particularly for their sons. Lamb suggests a final transition brings us to the focus of fatherhood today, which is on nurturing children. For the 'new nurturing father', emphasis is on being involved in the daily care of their children (Lamb 2000; Williams 2008). Today 'good' fathers face being judged by their involvement with children, as well as their performance of tasks valued in earlier phases of fatherhood (Williams).

Underscoring an emphasis on fathers as nurturers, social and economic conditions in the later third of the century prompted an increasing number of women (back) into the work force (Coakley 2006). Parenting meanings and practices in modern Western society have been profoundly gendered (Hojgaard 1997; Pleck 1997;

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Fox 2001; Coltrane 2004; Halford 2006), and as women re-entered the paid work force in increasing numbers, pressure has been exerted on resulting gaps in gendered responsibilities in the domestic sphere (White 1994). Pressures created by domestic work to be carried out after 'business hours' drive shifts in expectations surrounding fathering and families (Wall & Arnold 2007), and correspondingly, men experience tensions between the need to continue to fulfil a 'breadwinner' role, and the need/desire to be more 'involved' parents. Such tensions are intertwined with broader debates regarding 'modern masculinities', which are in transition, and filled with potential to leave men with feelings of vulnerability and uncertainty of their nature and purpose in the world (Williams 2009). Warin *et al.* (1999) argue cultural stereotypes, such as the breadwinning role, continue to hold men back from playing more active parenting roles, particularly in what are regarded as traditional 'mothering' activities. Fathers are squeezed between the 'new man' models, on the one hand, and the traditional cultural models of fathering, on the other (Williams 2008).

Nonetheless, as masculinity continues to evolve from traditional expectations for values of courage, inner direction, certain forms of aggression, autonomy, mastery, technological skill, group solidarity, adventure and toughness (Donaldson 1993), fathers are increasingly involved at home with their children. Particularly in dual-income households, men are taking increased responsibility for childcare, even if both men and women identify the mother as the primary caregiver (Williams 2008). Many fathers perform household and childrearing tasks their fathers never did (Coakley 2006). Fathers' increased time and involvement in the lives of their children is consistent with a shift to 'coparenting' as part of a contemporary form of masculinity (Pleck & Masciadrelli 2004). Research endeavours to draw out the involvement of fathers with their children are developing and some take the form of tracing changes to the amount of time fathers are available/engaged with their children. Pleck & Lamb (1997) averaged the results of such studies conducted during the 1980s and 1990s and concluded that fathers in two-parent intact families were engaged with their children 43% of the amount of time mothers were, and were accessible 65% of the amount of time that mothers were (Pleck & Lamb 1997). More recently, Yeung *et al.* (2001) found that fathers, in the year 1998, were spending 67% as much time as mothers on weekdays, and 87% as much time as mothers on weekends and researchers conclude that this increased engagement with children reflects evolving expectations of fatherhood as including hands-on care and nurturance (Lamb 2000). Claiming fathers' goals and actions depends on fathers' recollection of their own childhoods, Lamb & Tamis-LeMonda (2004) present findings of fathers' wishing to do better than their own fathers and regarding themselves as central in the lives of their children. Lamb & Tamis-LeMonda (2004) argue specifically that fathers choose to compensate for, or emulate, their own childhoods based on their interpretations of the parenting they received from their fathers. Elaborating on claims of fathers compensating for or emulating their own childhoods, Kindlon *et al.* (2000), from their study of fathers raising sons, conclude that fathers are partaking in reflective, deliberate parenting approaches; fathers are actively engaging in their child's care, wanting to do a good job with their child's care, wanting to do a good job in raising their child and wanting to do it better than their fathers did. At the same time, Williams (2008) argues, although fathers are aware of ideal types of fatherhood, their actions are in many ways determined by circumstances they have not chosen. Fathering is becoming increasingly individualized, as well as more reflexive, in response to circumstances that arise in the context of the changing expectations of fatherhood (Williams 2008).

While fathers' increasing participation in childcare and general involvement with their families are increasingly studied, several decades ago, Lamb (1975) called fathers 'forgotten contributors' to child development to highlight a history of understandings of parenting, and corresponding practice and policy, which have most often been derived from the perspective of mothers. More recently, Cassano *et al.* (2006) reviewed 702 empirical studies of child psychological adjustment, published between 1993 and 2005; 55% of these targeted mothers only, while 1% targeted fathers only. Of the 702 articles, only 28% included data from both mothers and fathers as well as included parent gender as a separate variable. The lack of focus on fathers in relation to child and adolescent psychopathology captured attention with Phares 'Where's Poppa' (1992) declaration and more recently in 'Still looking for poppa' (Phares *et al.* 2005). Indeed, our understandings about fathers' needs are derived from data far less extensive than those used to inform our understandings of the needs of mothers. A lack of research focus on fathers is mirrored in, and propelled by, family-centred practice and policy, which continues to be designed around expectations that a mother is readily available to advocate and care for her child (Dodd *et al.* 2009).

The growing prevalence of autism spectrum disorder (ASD) raises new opportunities for building understandings of fathering. ASD is the most common neurological disorder affecting children, with the number of children diagnosed each year increasing worldwide (Autism Society of Canada 2010). The Autism Society of Canada (2010) estimates there are more than 190 000 individuals with ASD in Canada and approximately 3000 new cases are identified each year. We know having a child with ASD poses distinct challenges and opportunities for fathers as some researchers report that fathers distance themselves from their child with ASD (Gray 2003; Pelchat *et al.* 2003), while others argue the presence of a disability is impetus for fathers to have greater involvement in their child's daily life (Stainton & Besser 1998).

Fathers of children with ASD

Parents of children with ASD face challenges related to their child's struggles with communication, emotional expression and antisocial behaviours (Gray 2006). These parents tend to report compromised quality of life (Lee *et al.* 2008) compared to parents of typically developing children and higher levels of stress (Benson & Dewey 2008; Mancil *et al.* 2009) than parents of typically developing children and children with disabilities such as Down syndrome (Sanders & Morgan 1997; Glasberg *et al.* 2006). How a family, and more specifically, a father, interprets a child's ASD and experiences stress associated with ASD will, to some degree, reflect broader social attitudes and historical realities in which his interpretations take place (Ferguson 2002). More than 50 years ago, Olshansky (1962) correlated having a child with a developmental disability to fathers' feelings of chronic sorrow; in Olshansky's study, fathers of children with developmental disabilities were presented as confronting the 'terrible reality' of their child's disability on a daily basis, comorbid with feelings of guilt, shame and anger. While research reports today tend to present fathers' experiences in more positive terms consistent with social advances in understandings of, and tolerance for, disabilities, fathers of children with ASD in Isenhour's recent study nonetheless reported a sense of loss and grief because they felt as if their expectations of what a 'typical child' should be – a reflection of the family and related significant others is lost along with the parents' hopes and expectations of achievement for their child (Isenhour 2010). Clearly, these fathers experience their roles in the context of socially prescribed fathering ideals for how fathers should behave and what fathers should expect from their child.

On the whole, fathers of children with ASD, compared to mothers, appear more sensitive to their child's label, less confident in their parenting abilities and less likely to seek and receive support in their parenting efforts (Sharpley *et al.* 1997). Fathers report more stress related to child temperament and emotional attachment difficulty, and greater challenges with the personal relationship to their children (Keller & Honig 2004). In the face of such stresses, parent support groups are aimed at providing social support within the educational or community setting to give parents an environment where they can discuss their difficulties, share coping strategies and accomplishments, and meet parents in a similar situations (Luther *et al.* 2005). However, fathers of children with disabilities, including ASD, may be unlikely to access support groups given fathers' relatively low rates of seeking (Sullivan 2002) and receiving (Altiere & von Kluge 2009) emotional and instrumental support for their parenting.

In the light of challenges experienced by fathers of children with ASD, Rodrigue *et al.* (1992) compared psychosocial adaptation of fathers who have children with autism versus children with Down syndrome versus children with normal development. These researchers describe their sample of fathers as seeing themselves as central in their child's care regardless of the presence or nature of their child's disability. This importance of fathers is often reflected in principle through policy goals of developing supports and services that are 'family-centred'. Definitions of family-centred practice vary but are anchored in beliefs that families are central to, and experts in, the needs of their children (Rosenbaum *et al.* 1998) and include partnership with and support for the whole family (Murphy *et al.* 1995). However, in practice, efforts to deliver and improve the impact of family-centred practices most often target mothers (Koegel *et al.* 1992; Boyd 2002; Rodger *et al.* 2008) who are assumed to be the central care figures in the lives of children; accordingly, fathers are relegated to a peripheral position.

In sum, messages persist that fathers in general are, and are expected to be, increasingly involved in the care of their children and, further, that fathers of children with ASD are distinctly impacted by added demands of their child's diagnosis. Yet supports are not well tailored to fathers' specific experiences and needs and far more work is required to understand and respond to fathers of children with ASD. In this study, we use an

ecological framework to with the goal of contributing to understandings of experiences and needs of fathers of children with ASD. We draw upon Bronfenbrenner's view (1994) of human development as nested in, and shaped by, layers of context and interactions between layers of context (1979; 1994). Contexts range from microsystems of immediate environment (e.g. coresident partner and child relationships) to macrosystems of social values and practices (e.g. expectations for good fathers) (Brofenbrenner 2009). Our ecological framework is visually represented as Figure 1 and used to sensitize our focus on how context influences fathers' views. The contexts we examine, driven by our review of the literature, are as follows: (i) having a child with ASD, given findings of distinct demands facing fathers of children with ASD; (ii) having been parented by their own fathers, given findings that fathers emulate or compensate for their own upbringings; (iii) parenting as part of the ASD community, given findings that ASD supports mainly target mothers; and (iv) parenting amidst contemporary societal expectations for good fathering, given findings that fathers are expected to nurture as well as provide for their children.

Methods

Anchored in our ecological framework, we used a narrative approach to collect and analyse qualitative accounts from fathers raising children with ASD about navigating their immediate and broader environments. We believe people use stories or consequential linking of events or ideas (Lal *et al.* 2012) to convey the richness of their 'internalized world' (Smith & Sparkes 2008), and we asked questions and invited fathers to share stories, about attending to their child's day-to-day needs for affection and daily care as well as about managing their child's needs in the community in terms of obtaining education and therapies. We tapped into fathers' experiences with more macrosystem expectations by asking how their parenting experience compared to parenting experiences of their wives, fathers of typically developing children and their own fathers.

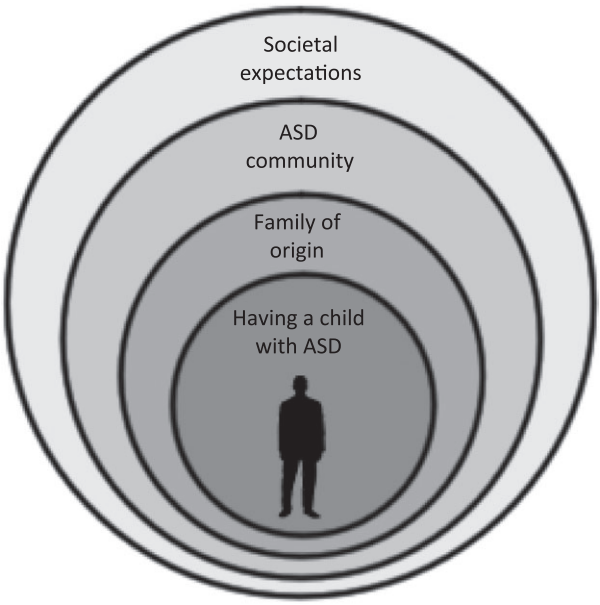

Figure 1 An ecological framework illustrating how context influences fathers' views.

Sample recruitment

Fathers of children with ASD were recruited through communication channels (newsletter, Websites and email distributions to members) of organizations providing advocacy, support, resources and services to families of children with ASD. Fathers responding to the call for participants were pre-screened over email or by telephone to ensure they meet inclusion criteria. To be included, fathers could be biological, step, adopted or foster, as well as single, common-law or married, and must have a child between the ages of 2 and 12 with ASD.

Sample composition and data collection

Twenty-eight fathers of children with ASD aged 2–12 years took part in face-to-face semi-structured interviews with one of two trained interviewers between January and April 2012. While the majority of fathers are married biological fathers of sons with ASD, two adoptive fathers, one divorced biological father and four biological fathers of daughters with ASD are also part of this sample. A set of questions was used to allow flexibility of the interview structure around predetermined topics yet allow flexibility to follow topics as introduced or elaborated by fathers. Relatedly, we did not offer choices of diagnostic ASD classifications from which fathers were required to select, but rather we recorded ASD type/severity in terms chosen by fathers.

Interviews lasted an average of 90 min and were digitally recorded and transcribed verbatim. Field notes were taken during the interviews as a record of points about which the interviewer wanted clarification. Fathers signed an informed consent form before their

interview; the voluntary nature of participation was highlighted as well as the risk that given the in-depth nature of the study, even though participants, and individuals named by participants, are assigned pseudonyms, there is potential for participants to be identifiable by people reading research reports who know participants and/or their families.

Analysis

In analysing our data, we conducted a thematic analysis using constant comparative methods per Onwuegbuzie *et al.* (2009). We began with repeated readings of interview transcripts and listening to corresponding audio files and organizing data into broad categories, or themes, according to our framework and related to fathers' experiences raising their child with ASD as influenced by experiences within fathers' family of procreation, family of origin, ASD community and society as a whole. Our analysis is semi-deductive in that we used our framework to look for how particular contexts influenced fathers' views, yet we remained open to all aspects – or subthemes – of contexts as identified by fathers. In generating subthemes, we followed Berg's practice (2004) of reflecting the main message of the data while retaining the wording of our participants as much as possible. We used Nvivo 10 qualitative data management software to help organize our data.

Trustworthiness

Data analysis was lead by the first author who met regularly with the second author and the broader research team, which included the interviewers who conducted the interviews, to discuss and develop interpretations. Several research team members were simultaneously analysing the shared data set to develop understandings on a number of topics for fathers of children with ASD such as fathers' use of leisure activities with their child with ASD, balancing employment versus family demands, and views of the impact of having a child with ASD on their marriages. Consequently, findings and interpretations for the current article were interrogated from multiple analytic perspectives within our team.

Members checking

During the interviews, investigators paraphrased and requested clarification and elaboration to enhance accuracy and completeness of the perspectives being shared by fathers. Fathers later received transcripts of their interview by email and were invited to provide clarification and elaboration. One father followed up by commenting that his responses were not as focused as he would have liked and that he hoped they would nonetheless be helpful to achieving study goals.

Findings

Fathering in the context of having a child with ASD

Fathers reflect on raising their child/children with ASD in terms of two subthemes: (i) transforming expectations, where fathers describe reconstructing their understandings of what fathering will look like, and (ii) amplified family life, where fathers describe amplification of family life and spousal partnerships as the family mobilizes to care for the child with ASD.

Transforming expectations

Fathers describe revising and redefining expectations for their child upon learning of their child's ASD diagnosis. Eli, father to 9-year-old Garrett with 'less severe' ASD as well as ADHD, says:

> 'I think the transition that I found difficult was that we are conditioned as we grow up to have kids and your kid is going to play hockey and your kid is going to do this and your kid is doing that. . .that was gone and it, you, you almost had to bury your, your conditioning so, so that son that I was going to have died and I have a new son and you have to learn, um, to build a new future and dream, or, or whatever. . .'

Grant, father to 8-year-old Jed with moderate ASD, speaks of revising his expectations:

> '[Having a child on the spectrum] takes the hard wired things that you know growing up and the, and what you know of a father son relationship, having a child on the spectrum challenges all of it, absolutely all of it'.

Despite challenges of revising expectations, father speaks of many rewards. Grant (Jed, 8, moderate ASD) says:

> 'So it's still very, very rewarding and, and very satisfying and, very, very challenging like, like all

> fathers with kids. They're just significantly different. The rewards come from places that isn't typical for fathers, you know he didn't make the, a certain hockey team which would be someone else's reward. Well for Jed, ah, it could be that he had a wonderful day at school'.

Amplified family life

Fathers' transformed expectations leave them attuned to their children's experiences such that they avoid taking their child's developmental achievements for granted. Grant (Jed, 8, moderate ASD) describes:

> 'As a father I still have the experience of watching my son go beyond himself and hit milestones and so I have the same joy and elation but probably amplified over most [typical] fathers 'cause they just, they don't realized how, how hard some of the stuff is'.

Although they give evidence of being aware of ideal images of fatherhood, fathers speak in terms of the relatively intense process of responding to circumstances of having a child with significant needs. Tristan, father to two sons with ASD, 15-year-old Duncan with severe ASD, and 11-year-old Elliot with moderate ASD, summarizes:

> 'I think having more intense circumstances to deal with might bring out characteristics or personality traits in a more prevalent way…'

Fathers express a heightened sense of needing to be involved with their children and work in strong partnership with their wives. Stan, father of three sons with ASD, 6-year-old Darren with mild ASD, 4-year-old Zack with moderate ASD and 4-year-old Raphael with severe ASD, speaks of tag-team parenting:

> '…you know our bond together has been strengthened because we need to be together for the sake of these three boys, um, so if it's, you know if it's Mom's day on let's say then, then I'll help support her, you know do stuff around the house or in the kitchen or whatever and then she'll take care of the boys and we just kind of tag team I guess. We complement each other…there has to be that cohesion I guess'.

Fathers also discuss the importance of being involved at home so their wives can have a break. Jason, father to 4-year-old Brett with moderate ASD, says:

> '…I come home and it's job number two starts until, you know at least until the youngest one's gone to bed and then there's still dishes to clean up and you know life (chuckle) goes forward, your household chores so I think we've discussed…I tried to be as fair as possible… I really pick it up on the weekends you know because [my wife] has been with Brett for five days, I really try and pick up the majority of his needs during the weekend. Um, same thing in the evenings and bath time and bedtime and stories and, and that sort of thing. She's done that all day already'.

Marvin, the father to 3-year-old Lonny with severe ASD, says: 'So I don't know I mean, I try to do something with [my son] every day right and I think that gives Megan a bit of a break'.

Fathers who describe their experiences in the context of having a child with ASD highlight their work to redefine expectations and give evidence of continued efforts to be attuned to their child's ASD-specific needs and the implications of these needs for their wives.

Fathering in the context of family of origin

Fathers articulate choices about what they compensate for, versus emulate, based on reflections of their own upbringings combined with expectations they hold for their children. Accordingly, our two subthemes are as follows: (i) first subtheme is compensating for their fathers' absence, which includes support for their own fathers' parenting through awareness of fatherhood in social/historical context as well as disapproval of their own father's parenting in the form of their own endeavours to break a family cycle. Our second subtheme is (ii) emulating the modelling of values exemplified by their own fathers.

Compensating for absence

Fathers share recollections of their fathers' absence from their lives and describe their own day-to-day involvement with their children including in efforts at 'breaking a family cycle'. Although some fathers view their own fathers' absence as part of expectations of the era, they are clear about their own efforts to do things

differently with their own children. Marvin (Lonny, 3, severe ASD) notes:

> 'If you were to compare [my relationship with Lonny to the relationship I had with my father] there's no loving or nurturing received from my father whereas I give lots to my son. [My father] did the best with me with the you know knowledge he had in terms of raising, ah, raising me but I mean my aggregate amount of time with my son has already surpassed what my Dad has spent with me in [my entire life]'.

Stan (Darren, 6, mild ASD; Zack, 4, moderate ASD; Raphael, 4, severe ASD) is troubled by his inaccessible father yet notes that expectations were different in his father's day:

> 'I understand where my Dad is coming from and I don't hold it against him. It's. It's the way you're raised. He's, he was born in 1945 in the war so you know small town farmer, ah, it's just different, things are different, not better not worse, just different'.

Yet like others in our sample, Stan believes that being a busy breadwinner is no excuse to be emotionally and physically unavailable to one's children:

> 'He was there, um, but he had his own business so he was working a lot, you know and the old excuse well I'm doing it for my family which now that I'm a dad, I don't buy it'.

Marvin (Lonny, 3, severe ASD) describes his effort to be different than his own father as 'breaking a family cycle':

> 'Ah, the only way to kind of break a family cycle is to create a new one right. It's to pass on the behaviours that I mean I hope, you know I hope Lonny grows in as a family and I hope that some of the behaviours that I've you know modeled for him are emulated in the future'.

Emulating

Fathers express admiration, and efforts to emulate, parenting practices of their own fathers. Although each emulating father admires different aspects of his father, all attribute their positive experience to their fathers' having role-modelled life skills such as independence, maturity, responsibility, patience and respect, aspects of their own childhood which fathers endeavour to re-enact. Dan, father to 8-year-old Cade with severe ASD, and 6-year-old Chantal with moderate ASD, notes:

> '[My father] treated me like, like a little man and, and, and I developed a certain sense of, of, ah, independence and maturity and all that stuff when I was working with him and, and that's the kind of, ah, expectation that I would have of a relationship with my own son, you know at a certain stage you know start treating him like a little man, make him feel responsible'

Andrew, father to 4-year-old Kimberley with mild–moderate ASD, is explicit in his claim that fathering approaches flow from father to son:

> 'I think that comes to the father and how much, um, they want to be involved in the child's life so my Dad was very, very good and wanted to be involved with me and I think that passes on from generation to generation'.

Like being attuned to the needs of their children and wives, fathers emulating and compensating for their own upbringings provide evidence of reflective, responsive parenting.

Fathering in the context of the ASD community

Fathers describe their experiences and needs relative to access to resources as part of the ASD community and illustrate our first subtheme, (i) finding the right kind of support. Finding the right kind of support is comprised of distinctions between (a) traditional versus non-traditional support, (b) giving versus receiving support and (c) helping versus hindering support. Fathers also point to the importance of our second subtheme of (ii) finding the right time and place for support in the light of demands of family and work.

Finding the right kind of support

Fathers describe challenges in acquiring funding and services for their child. Grant (Jed, 8, high-functioning ASD) speaks of the skills and perseverance required:

> 'Um, Jill and I, um, have a high level of education, have a high level of experience dealing with, ah, organizations and, and the challenges and we're

very, ah, focused and, and are very strong advocates for Jed, um, and so, ah, if you work very hard and you do your homework and you have some financial means, um, you can typically get a lot of the resources…as parents you need to be very, very strong advocates and you have to help identify the priorities and if they happen to be gr-great. If not then you need to stick to your guns'.

Traditional versus non-traditional supports. Fathers compare non-traditional versus traditional support and several express preference for non-traditional approaches that do not require participants to 'sit down and talk about their feelings', but rather promote support through shared experiences.

Eli (Garrett, 9, less severe ASD and ADHD) suggests:

'Um, that you is there a, maybe there's a camping trip that some fathers are going to take their kids on. I'll take my son and then we could all at least we're kind of, maybe we organize and go camping together so you know I go camping and I'm on my own and you know I get the kids to bed and I sit around the campfire and take a sigh of relief and have a few beers you know, but you know it would be nice to hang out with someone else…'

Other fathers find meaning in more traditional support as evidenced in Tristan's (Duncan, 15, severe ASD; Elliot, 11, moderate ASD) reflections on running a fathers-only group:

'…we've done a Dad's support group, ah, and I'll talk about that 'cause the attendance was amazing and the emotional, um, intensity was shocking (chuckle). I, I found a lot more truths on the table, more emotions on the table than any support group that I've done that was predominantly female'.

Giving versus receiving. Fathers, particularly those with an older child with ASD, and corresponding lengthy experience accessing ASD-related supports, express interest in mentoring families who have a newly diagnosed child. Jason (Brett, 4, moderate ASD) speaks of wanting to give back:

'…I mean we know so much about [ASD], you know if we could help other families that, to get through. I mean it's a tough time in, in a, you know in a family to have to deal with all this and a lot of people don't have the resources or the where with all to, to pull that together, so we'd like to kind of give back to that…'

Similarly, Stan (Darren, 6, mild ASD; Zack, 4, moderate ASD; Raphael, 4, severe ASD) says:

'It's absolutely essential that people have support because I, I feel I'm a strong person. Maybe I can go and help someone else'.

Helping versus hindering. Fathers express apprehension about discussing their child's ASD symptoms in front of other parents who may pass judgement. For example, Fred, father to 12-year-old Trafford, who has severe ASD, describes having attended a support session for parents of children with ASD shortly after Trafford was diagnosed only to have Trafford's symptoms downplayed:

'…Janessa and I are devastated and she's like say well does Trafford watch TV, I'm like yeah Trafford watches TV and she was like oh you're so lucky he watches TV 'cause my kid doesn't watch TV very much and you know my kid has to do this but you guys are so lucky that you have, like what the heck you know, it's like one I thought you were supposed to listen to us. Two, this is not the time to sit there and tell me how fortunate I am you know'.

Fathers also point out judgement between parents regarding decisions to pursue treatments or medical interventions, as well as choices to vaccinate subsequent children born. Victor, the father to 7-year-old Kevin with moderate-to-severe ASD, highlights:

'I think where parents suffer is with the snake oil. The, try anything … there's an awful lot of judgment within the community. Your kid's not on a diet, how dare you! You're going to vaccinate your next child. How dare you! There is an awful lot of judgment because you're seeking the miracle, because there is not a clear understanding of the cause, you look for any explanation to explain what happened…'

The right time and place

Fathers convey interest in interacting with other parents of children with ASD, but emphasize having limited

time between work, caregiving and having time to regenerate. Ethan, father to 7-year-old Noah with severe ASD, observes:

> 'You know it's one of these things were you know, ah, it's a, I'm going to mix metaphors and say it's a vicious cycle and I'm not sure which is the chicken and which is the egg but, ah, probably we could benefit I suppose from interacting with others but we don't have time to'.

Fathers point to evenings and weekends as most convenient times for attending support activities and also note location and childcare as barriers. Dan (Cade, 8, low-functioning ASD; Chantal, 6, moderate-functioning ASD) offers:

> 'Events that involved the kids on the weekends would be the best way, you know, the stuff, stuff that was inclusive of families I think is a better, better situations that something that's just like well leave your kids and come and sit down and talk with these adults'.

Isaac, father to 4-year-old Reid, with high-functioning ASD, endorses the appropriateness of support activities which include his son: 'If it was nearby and quick and Reid could come, that would probably work'.

'Making it easy'

Russell, father to 4-year-old Emerson with mild ASD, suggests the value of matching families/fathers with particular support services:

> 'What would be cool is just to have a list of or, ah, there's so many lists. Have a, a, a, an assessment by someone and they say we think these are the groups that would be able to help you the most and, um, so we've given your name to such and such and such and such and they'll be in contact with you…'

Part of fathers' reflective, responsive parenting approaches include well-defined ideas about the kinds of support that is, or could be, helpful.

Fathering in the context of societal expectations

Fathers reflect masculinities in diverse ways as they describe their roles relative to their children. William, father to 9-year-old Brandon with mild ASD, describes his traditional enactments of masculinity:

> 'I'm an A type personality. That's just who I've always been. That's, ah, I'm, I'm the one affectionately you would say who wear the pants in my family… For a guy like me who's the alpha male, ah, when you're in protective mode and you're in a very analytical mode and aggressive mode which I often find myself with my son…'

Contrasting with William, Chris, father to 3-year-old Leroy with 'autism light', describes playing a stereotypically feminine role as he stays home with Leroy, while his wife works full-time outside the home:

> 'I, I'm you know, I'm Mr. Mom. I, I', not a hero but I do all the, ah, I do all the chores… I do my laundry, I do Leroy's, I do the floors, I do the ta- I've taken on the role of I do the cooking, or barbequing actually. I'm passionate about it ah, so, so yeah I do all of it, you know Monday to Friday. That's my job'.

Dan (Cade, 8, low-functioning ASD; Chantal, 6, moderate-functioning ASD) depicts masculinity in terms of wrestling with feelings of needing to have everything under control:

> '…we're tough guys. We, we're going to deal with it you know. I think you know you soldier on, you know you're a Dad, your, your job is to raise those kids and by God you're going to do it, whatever it take you know and just you, you know you, you commit…'

Dan goes on to describe how expectations to be 'tough guys' leaves fathers' feeling, or at least, acting, confident and such behaviour does not entail seeking and accepting help:

> '…we fathers tend to, ah, I guess feel whether or not it's justified and warranted. We tend to feel fairly confident in our ability to manage you know, ah, this, I think that's just a universal thing that men kind of feel you know and there are days where you feel inadequate and but you're not sure, you know it's hard, to get tangible help you have to kind of know I guess have an idea of what kind of help you need, um, you know sure I mean I'd love for someone to come in and show me some new

strategies of how to play with Cade, how to engage that boy, you know how to get that boy happy and, and, and just connected to you and looking you in the eye all the time and yeah, probably could use some help. I'm not sure how, what kind of form or shape that would come in'.

Relatedly, William (Brandon, 9, High-Functioning ASD) describes how resources built around traditional assumptions of masculinities can be disenfranchising to fathers:

'. . .because it is so challenging, the, the reinforced message needs to be here that this needs to be done in tandem and that the solutions or the assistance that's, that's offered or suggested needs to apply equally to both men and women and if the message is consistently skewed toward women, then you start to disenfranchise men because they don't, they can't relate to the information, they can't, ah, see where they necessarily fit in and then they start to move away from the process because they just don't feel it's applicable to them. . .'

William reflects on the unrealized potential of fathers who feel on the periphery of supports and services:

'. . .and the men are them in my humble view here, the silent voice in this that can play a far larger role than is either offered to them or is even contemplated and those family structures that I have witnessed at the school or pre or other schools we've been involved in, the children that do the best are the ones that have both parents actively engaged and that's, so I, I just say that as, as sort of [an] overarching theme'.

Fred (Trafford, 12, severe ASD) adds to this line of thinking as he discusses the disproportion of programmes available for mothers versus fathers of children with ASD:

'Um, but there's not a lot as a, as a Dad. You know as a Mom I think there was more. . .I think there's more things that are geared towards Moms and I think that's just and you know like schools you know they, they have coffee things like that and they're thinking about the Moms right. You know they're in the middle of the day and you know um, and Dads you know there's a little bit, you know maybe it's machismo, maybe it's stereotyping, you're a little tough guy you know so you don't need that as much. . ..'

Oliver, father to 3-year-old Troy with PDD-NOS, discusses a need for more contouring to father-specific needs:

'[Services address my priorities as a father] to the extent that those are aligned with the family, yes, but they don't have a separate father or mother you know what do you, what do you want as a mother or what do you want as a father explicitly part of the process. . ..'

As fathers navigate raising their children with ASD, they express awareness of restrictions imposed by societal expectations along with suggestions for how such restrictions might be counteracted.

Discussion

Having a child with a disability is often assumed to be a negative and substantially challenging experience. A prevalent research stance has been that when a child with a disability is born, the disability overwhelms all other considerations (Olshansky 1962; Byrne & Cunningham 1985; Stainton & Besser 1998; Crnic *et al*. 2002; Ferguson 2002). Ferguson (2002) counters ideas of the overwhelming power of disability quoting the conviction of a study participant parent of a child with a disability: 'The most important thing that happens when a child with disabilities is born is that a child is born. The most important thing that happens when a couple becomes parents of a child with disabilities is that a couple becomes parents' (Ferguson & Asch 1989). While we do not contest that parents of children with disabilities face considerable challenges throughout their child's lifetime, our data provide a vivid illustration of fathers of children with ASD engaging in and enjoying fathering as they innovatively manage their children's care needs and insightfully make sense of their parenting and the types of supports that might help.

Fathers are attuned to understanding and responding to their child's needs as well as reflective about how their understandings and responses constitute their own approaches to fathering. Although many fathers in this study ascribe to traditional breadwinning roles within their families, spending time with their children is central. Disability-specific demands provide impetus for father–child time and part of this impetus is a relatively pronounced sense of the need to work in partnership

with their wives, not only to ensure the needs of the children are well met, but also so each parent has opportunity to pursue individual interests. Fathers are concentrated on meeting the needs of their children in ways that compensate for what they perceive as deficiencies in their own upbringings. Fathers are, in effect, amending the fathering style that was their first frame of reference while appreciating fathering practices as rooted in social/historical context. Fathers describe their own fathering practices within broader contexts of the ASD community through which they carefully navigate supports, and amidst social conventions where masculinity entails 'being in control' in ways that collide with the unpredictability of ASD. Through these multicontext considerations, fathers invite critical re-examination of mother-focused structures and practices and leave us with recommendations for increasing the father-friendly quality of supports.

Fathers offer some endorsement for traditional (parent or father specific) support groups yet caution about potential harmful judgments that can occur between participants, and accordingly, we recommend support efforts targeting fathers be predicated on regard for the individual, and indeed, idiosyncratic, character of parenting a child with ASD. Fathers also point to the appeal of recreationally based support activities where they can engage with other fathers of children with ASD with their children in attendance. Perhaps the relatively immediate quality of activity-based supports inclines energy away from problematic passing of judgments. At the same time, fathers emphasize challenges in attending support activities in the light of their need to balance employment, childcare demands and finding time to regenerate. For this sample of fathers, support activities scheduled on weekends seem preferable. Finally, fathers in our sample highlight the value of father to father support; specifically, fathers are attuned to struggles entailed in coming to terms with a child's ASD diagnosis and interested in using their experiences to mentor fathers newer to the experience of having a child with ASD.

Conclusion

This study is limited to a sample of fathers of relatively high socio-economic status who are part of intact families and have high levels of involvement with their children. We recommend, and look forward to being part of, continued research efforts to capture in-depth perspectives of fathers of children with ASD who are from a wider range of socio-economic and family structure backgrounds. At the same time, the depth of our evidence of fathers' enthusiasm in nurturing their children is an important contribution to understandings of parenting children with disabilities as more than problem-focused, and understandings of men's parenting as engaged and resourceful.

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References

Altiere M. J. & von Kluge S. (2009) Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies* **18**, 83–92.

Autism Society of Canada (2010) *Prevalence in Canada*. Available at: http://www.autismsocietycanada.ca/index.php?option=com_content&view=article&id=66&Itemid=105&lang=en (accessed on 6 March 2011).

Benson B. & Dewey D. (2008) Parental stress and needs in families of children with autism spectrum disorder. *International Journal of Disability, Community & Rehabilitation* **7**, 1–9.

Berg B. (2004) *Qualitative Research Methods for the Social Sciences*. Pearson Education, Boston.

Boyd B. A. (2002) Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities* **17**, 208–215.

Bronfenbrenner U. (1994) Ecological models of human development. *Readings on the Development of Children* **2**, 37–43.

Bronfenbrenner U. & Bronfenbrenner U. (2009) *The Ecology of Human Development: Experiments by Nature and Design*. Harvard University Press, Cambridge, MA, USA.

Byrne E. & Cunningham C. (1985) The effects of mentally handicapped children on families–a conceptual review. *Journal of Child Psychology and Psychiatry* **26**, 847–864.

Cassano M., Adrian M., Veits G. & Zeman J. (2006) The inclusion of fathers in the empirical investigation of child psychopathology: an update. *Journal of Clinical Child and Adolescent Psychology* **35**, 583–589.

Coakley J. (2006) The good father: parental expectations and youth sports. *Leisure Studies* **25**, 153–163.

Coltrane S. (2004) Elite careers and family commitment: it's (still) about gender. *The Annals of the American Academy of Political and Social Science* **596**, 214–220.

Crnic K. A., Friedrich W. N. & Greenberg M. T. (2002) Adaptation of families with mentally retarded children: a model of stress, coping, and family ecology. *Best of AADD: Families and developmental delay: AA collection of notable AADD journal articles across the 20th century*, 105–117.

Dodd J., Saggers S. & Wildy H. (2009) Constructing the 'ideal'family for family-centred practice: challenges for delivery. *Disability & Society* **24**, 173–186.

Donaldson M. (1993) What is hegemonic masculinity? *Theory and Society* **22**, 643–657.

Ferguson P. M. (2002) A place in the family an historical interpretation of research on parental reactions to having a child with a disability. *The Journal of Special Education* **36**, 124–131.

Ferguson P. & Asch A. (1989) Lessons from life: personal and parental perspectives on school, childhood, and disability. In: *Disability and Society* (eds Biklin D, Ford A & Ferguson D), pp. 108–140. National Society for the Study of Education, Chicago.

Fox B. (2001) The formative years: how parenthood creates gender*. *Canadian Review of Sociology/Revue canadienne de sociologie* **38**, 373–390.

Glasberg B. A., Martins M. & Harris S. L. (2007) Stress and coping among family members of individuals with autism. In: *Stress and Coping in Autism* (eds M. G. Baron, J. Groden, G. Groden & L. P. Lipsitt), pp. 277–301. Oxford, New York.

Gray D. E. (2003) Gender and coping: the parents of children with high functioning autism. *Social Science & Medicine* **56**, 631–642.

Gray D. E. (2006) Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research* **50**, 970–976.

Halford S. (2006) Collapsing the boundaries? Fatherhood, organization and home-working. *Gender, Work & Organization* **13**, 383–402.

Hojgaard L. (1997) Working fathers-caught in the web of the symbolic order of gender. *Acta Sociologica* **40**, 245–261.

Isenhour J. A. (2010) *Experiences and Perceptions of Fatherhood Among Fathers With Sons Who Have Autism Spectrum Disorders*. Appalachian State University, Boone, North Carolina.

Keller D. & Honig A. S. (2004) Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry* **74**, 337–348.

Kindlon D. J., Thompson M. & Barker T. (2000) *Raising Cain: Protecting the Emotional Life of Boys*. Random House Digital, Inc., New York.

Koegel R. L., Schreibman L., Loos L. M., Dirlich-Wilhelm H., Dunlap G., Robbins F. R. & Plienis A. J. (1992) Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders* **22**, 205–216.

Lal S., Suto M. & Ungar M. (2012) Examining the potential of combining the methods of grounded theory and narrative inquiry: a comparative analysis. *The Qualitative Report* **17**, 1–22.

Lamb M. E. (1975) Fathers: forgotten contributors to child development. *Human Development* **18**, 245–266.

Lamb M. E. (2000) The history of research on father involvement. *Marriage & Family Review* **29**, 23–42.

Lamb M. E. & Tamis-LeMonda C. S. (2004) Chapter title. In: *The Role of the Father in Child Development*, 4th edn (ed. M. E. Lamb), pp. 12. John Wiley & Sons Inc., Hoboken, New Jersy.

Lee L.-C., Harrington R. A., Louie B. B. & Newschaffer C. J. (2008) Children with autism: quality of life and parental concerns. *Journal of Autism and Developmental Disorders* **38**, 1147–1160.

Luther E. H., Canham D. L. & Cureton V. Y. (2005) Coping and social support for parents of children with autism. *The Journal of School Nursing* **21**, 40–47.

Mancil G. R., Boyd B. A. & Bedesem P. (2009) Parental stress and autism: are there useful coping strategies? *Education and Training in Developmental Disabilities* **44**, 523.

Morman M. T. & Floyd K. (2002) A "changing culture of fatherhood": effects on affectionate communication, closeness, and satisfaction in men's relationships with their fathers and their sons. *Western Journal of Communication (Includes Communication Reports)* **66**, 395–411.

Murphy D. L., Lee I. M., Turnbull A. P. & Turbiville V. (1995) The family-centered program rating scale an instrument for program evaluation and change. *Journal of Early Intervention* **19**, 24–42.

Olshansky S. (1962) Chronic sorrow: a response to having a mentally defective child. *Social Casework* **43**, 190–193.

Onwuegbuzie A. J., Dickinson W. B., Leech N. L. & Zoran A. G. (2009) Toward more rigor in focus group research: A new framework for collecting and analyzing focus group data. *International Journal of Qualitative Methods* **8**, 1–21.

Pelchat D., Lefebvre H. & Perreault M. (2003) Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care* **7**, 231–247.

Phares V. (1992) Where's poppa? The relative lack of attention to the role of fathers in child and adolescent psychopathology. *American Psychologist* **47**, 656.

Phares V., Fields S., Kamboukos D. & Lopez E. (2005) Still looking for poppa. *Psychologist* **60**, 732–734.

Pleck E. H. (1997) Paternal involvement: levels, sources, and consequences. In: *The Role of the Father in Child Development*, 3rd edn (ed. Lamb ME), pp. 66–103. John Wiley & Sons Inc., New York.

Pleck J. H. & Masciadrelli B. P. (2004) Paternal involvement by US residential fathers: levels, sources, and consequences. *The Role of the Father in Child Development* **4**, 222–271.

Rodger S., Keen D., Braithwaite M. & Cook S. (2008) Mothers' satisfaction with a home based early intervention programme for children with ASD. *Journal of Applied Research in Intellectual Disabilities* **21**, 174–182.

Rodrigue J. R., Morgan S. B. & Geffken G. R. (1992) Psychosocial adaptation of fathers of children with autism, Down syndrome, and normal development. *Journal of Autism and Developmental Disorders* **22**, 249–263.

Rosenbaum P., King S., Law M., King G. & Evans J. (1998) Family-centred service: a conceptual framework and research review. *Physical & Occupational Therapy in Pediatrics* **18**, 1–20.

Sanders J. L. & Morgan S. B. (1997) Family stress and adjustment as perceived by parents of children with autism or Down syndrome: implications for intervention. *Child & Family Behavior Therapy* **19**, 15–32.

Sharpley C. F., Bitsika V. & Efremidis B. (1997) Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability* **22**, 19–28.

Smith B. & Sparkes A. C. (2008) Narrative and its potential contribution to disability studies. *Disability & Society* **23**, 17–28.

Stainton T. & Besser H. (1998) The positive impact of children with an intellectual disability on the family 1. *Journal of Intellectual and Developmental Disability* **23**, 57–70.

Sullivan A. (2002) Gender differences in coping strategies of parents of children with Down syndrome. *Down Syndrome Research and Practice* **8**, 67–73.

Wall G. & Arnold S. (2007) How involved is involved fathering? An exploration of the contemporary culture of fatherhood. *Gender & Society* **21**, 508–527.

Warin J., Solomon Y., Lewis C. & Langford W. (1999) *Fathers, Work and Family Life*. Family Policy Studies Centre, London.

White N. R. (1994) About fathers: masculinity and the social construction of fatherhood. *Journal of Sociology* **30**, 119–131.

Williams S. (2008) What is fatherhood? Searching for the reflexive father. *Sociology* **42**, 487–502.

Williams R. A. (2009) Masculinities and fathering. *Community, Work & Family* **12**, 57–73.

Yeung W. J., Sandberg J. F., Davis-Kean P. E. & Hofferth S. L. (2001) Children's time with fathers in intact families. *Journal of Marriage and Family* **63**, 136–154.