

## "I'm hoping, I'm hoping...": Thoughts About the Future from Families of Children with Autism or Fetal Alcohol Spectrum Disorder in Ontario

### Abstract

*Applying hope theory, this mixed methods study compared the experiences of families raising children with FASD with families of children with autism and specifically their thoughts about their children's futures. Participants filled out two questionnaires, the Parenting Stress Index – Short Form and the Hope Scale. They also participated in in-depth semi-structured interviews. Questionnaire responses revealed that parents of both disability types have several fears for the future, but no significant differences were found between participant groups on the quantitative measures. Although parents of children with both disability types discussed similar concerns for the future in interviews (anxieties regarding level of independence, educational and vocational concerns, and fear of harm), there were qualitative differences in their anxieties. While recognizing that life may be harder, families of children with autism were hopeful when they spoke about future possibilities; that their children would be fully independent, educated, meaningfully employed, and married with children. In contrast, families of children with FASD recognized their lack of hope for their child's future, citing difficulties establishing independent living, education, employment, and significant positive relationships with peers and/or partners. Parents of children with FASD also accepted that life might include jail, teen pregnancy, and other adversity. Results are discussed with reference to community awareness and supports available for families of children with autism and FASD. The importance of mixed methods research is also highlighted.*

Researchers have suggested for decades that having a child with a disability is indisputably associated with the experience of parenting stress (see Watson, Hayes, & Radford-Paz, 2011 for a historical review). However, different disability diagnoses present specific strengths and challenges that may impact the experience of parenting stress (Dykens & Hodapp, 2001). To illustrate the unique experiences of parents associated with the diagnosis of their child, this article compares families of those diagnosed with Fetal Alcohol Spectrum Disorder (FASD), to those diagnosed with Autism Spectrum Disorder (autism).

FASD refers to the continuum of physical, cognitive, and behavioural abnormalities caused by prenatal alcohol exposure, with possible labels of fetal alcohol syndrome (FAS), partial FAS, fetal alcohol effects, alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004). Individuals with FASD have cognitive and behavioural

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deficits, and the interaction of these vulnerabilities can lead to “secondary disabilities,” including mental health problems, trouble with the law, and inappropriate sexual behaviour (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Streissguth et al., 2004). The Canadian prevalence rate of FASD ranges from 1 to 6 in 1000 live births (Stade, Ungar, Stevens, Beyen, & Koren, 2007).

Similar to FASD, autism is a spectrum disorder that includes a range of developmental disorders, including autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger’s syndrome (American Psychiatric Association [APA], 2000). Autism is a biologically based neurodevelopmental disorder (Matson & Kozlowski, 2011), characterized by deficits in social interaction, communication, and restricted and/or ritualized interests, behaviours, or activities (APA, 2000). The current prevalence of autism is estimated at approximately 1 in 100 live births (Baron-Cohen et al., 2009; Matson & Kozlowski, 2011).

## **Families of Children with Disabilities**

Despite a long history of research on the stress faced by parents of children with an intellectual disability (ID) (e.g., Kenny & McGilloyay, 2007; Wikler, Wasow, & Hatfield, 1981) or autism (e.g., Abbeduto, Seltzer, & Shattuck, 2004; Eisenhower, Baker, & Blacher, 2005), there is a dearth of research considering the experience of parents of children with FASD (Watson, Coons & Hayes, 2013). However, some researchers have found that family characteristics may contribute to the experience of parenting stress for families of children with FASD (Olson, Oti, Gelo, & Beck, 2009; Paley, O’Connor, Frankel, & Marquardt, 2006; Paley, O’Connor, Kogan, & Findlay, 2005). For example, in families with low socioeconomic status, having fewer family resources to advocate for and support their children predicted higher maternal stress in biological mothers of children with FASD (Paley et al., 2005). Parents of children with FASD often face unique stressors due to a lack of knowledge or awareness about FASD in the community, as well as amongst professionals (Caley, Winkelman, & Mariano, 2009; Ryan, Bonnett, & Gass, 2006; Watson, Hayes, Coons, & Radford-Paz, 2013).

In comparison, parents of children with autism have reported that the core deficits associated with their child’s diagnosis (impairments in social communication and restricted/repetitive behaviours) are particularly stressful (e.g., Davis & Carter, 2008; Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2005). Families of children with autism commonly experience behavioural challenges associated with a wide range of externalizing behaviours (i.e., hyperactivity, irritability, aggression, oppositionality, self-injury; Lecavalier, Leone, & Wiltz, 2006) and internalizing behaviours (i.e., depression, anxiety; Simonoff et al., 2008). Beyond child characteristics, long-term uncertainty about their child’s level of functioning and future potential, as well as their family’s ability to address those needs, can add to parents’ reported stress (Kermanshahi, Vanaki, Ahmadi, Kazemnejad, & Azadfalsh, 2008; Raina et al., 2005).

Parents of children with disabilities often describe anxiety over the future security of their children when they would no longer be able to provide care (Foster, Kozachek, Stern, & Elsea, 2010; Heller, Caldwell, & Factor, 2007; Kenny & McGilloyay, 2007; van den Borne et al., 2006). Families of children with autism in particular have identified concerns about the future as a significant contributor to their experience of stress (Bayat, 2007; Pisula, 1996; Sharpley, Bitsika, & Efremidis, 1997). One study identified fear for the future as higher among families of children with autism in comparison to those of children with Down syndrome (Pisula, 2007), while another study identified pessimism (the expectation of future self-sufficiency) towards their child’s future as higher in families of children with autism in comparison to those of children with Down syndrome (Sanders & Morgan, 1997). Although several studies have suggested that parents of children with autism are uncertain about their child’s future, most parents do not abandon hope that a significant change in their child will occur (Bilgin & Kucuk, 2010; Dale, Jahoda, & Knott, 2006; Fleishmann, 2005). While recognizing their child’s limitations, parents appear to have fairly high expectations for positive outcomes. Despite the fact that most parents understand that their child will never behave as other children who are “typically developed” (Fleishmann, 2005), Bilgin and Kucuk (2010) found that 51% of their sample of parents of

children with autism expected major improvements in their children's overall functioning.

Although there have been fewer studies on families of children with FASD, researchers have suggested that both biological and adoptive parents have considerable fear for their child's future (Gardner, 2000; Olson et al., 2009; Salmon, 2008; Sanders & Buck, 2010). In particular, parents must contend with the possibility that their children will be dependent on some sort of formal support throughout their lives, and that their role as the primary caregiver will not end when their children turn 18 years old (Olson et al., 2009; Sanders & Buck, 2010). In addition, foster parents reported that they were quite concerned about their children's safety, fearing that because of their trusting and naïve natures, their children with FASD would be taken advantage of by peers (Gardner, 2000). Likewise, birth mothers have spoken about their children's lack of social skills and feared they would be unemployable in the future, would violate the law, and be incarcerated (Salmon, 2008).

From the limited literature available, there appears to be a difference between future expectations of families with children with autism and those of children with FASD. Families of children with autism often expect improvement of challenging behaviours, while families of children with FASD often expect deficits resulting in lifelong consequences (e.g., trouble with the law). In summary, parents of children with FASD appear to have less hope about their child's future; however, no study has compared parents of children from both types of families on the same measures, using the same methodology. Moreover, to the authors' knowledge, no studies have employed hope theory to study parents' thoughts about the future.

## Hope Theory

Snyder and colleagues (1991) described hope theory as a model based on the old adage "where there is a will, there is a way" (p. 571). Hope theory is a system of goal-attainment behaviour characterized by agency (will) and pathways (way) thinking. Agency thinking is conceptualized as having the motivation to initiate and sustain effort towards a goal, while pathways thinking is having the ability to per-

ceive, plan, implement and adjust ways to reach that goal, and the ability to adapt those pathways when needed, such as when faced by an unexpected barrier (Snyder, 2002; Snyder et al., 1991; Snyder et al., 1996).

Higher levels of hope have been identified in both resilient individuals (Snyder et al., 1991) and families (Lloyd & Hastings, 2009). Researchers have found that higher hope predicts overall life satisfaction, contributes to both psychological and physical well-being, and may be a factor that facilitates positive life changes (Shorey, Little, Snyder, Kluck, & Robitschek, 2007; Snyder, Feldman, Taylor, Schroeder, & Adams, 2000). In general, successful people lead goal-directed lives, have positive expectations for the future, and actively work towards attaining them by utilizing more agency and pathways thinking (Seligman, 2002; Valle, Huebner, & Suldo, 2006). In fact, it is the active nature of hope that distinguishes it from other theories, such as optimism. For example, hope theory emphasizes the reciprocal relationship between agency (feelings of efficacy) and pathways (outcome expectancy), while optimism is more the expectation or belief that positive outcomes will occur (Peterson & Seligman, 2004; Snyder et al., 1991). In other words, optimism is the belief that things will work out, while hope is the active process of working to ensure the desired outcome is achieved; in this regard, hope is also being future-minded or future-oriented (Peterson & Seligman, 2004).

In addition, researchers have found that hope is negatively correlated with depression and anxiety and positively correlated with life satisfaction (e.g., Arnau, Rosen, Finch, Rhudy, & Fortunado, 2007; Chang, 2003; Lloyd & Hastings, 2009). Furthermore, individuals with higher hope may experience more positive emotions than those with lower hope (Oettingen & Gollwitzer, 2002). In studies investigating hope theory in families of children with an intellectual disability (Lloyd & Hastings, 2009) or families of children with chronic physical conditions (e.g., spina bifida, cerebral palsy, or insulin-dependent diabetes; Horton & Wallander, 2001), researchers have suggested that hope may play an important role when families are adjusting and adapting to their child's condition or disability. For families of children with a disability, when the goal is to restore family

functioning following a crisis (i.e., when the family's demands have exceeded their capabilities), it follows that hope would be required to foster resiliency (Watson & Hayes, 2011).

It has been suggested that parenting stress is associated with being uncertain about the future of a child diagnosed with a disability because the family's goals and expectations for the child are threatened (Wong & Heriot, 2008). Therefore, the authors of the present study investigated the experience of parents with regards to the future of their children, and the role that hope may play in their family's ability to overcome goal-blockages and foster their belief in positive outcomes.

## Methodology and Methods

The findings presented in this paper stem from a larger mixed methods study that compared families of children with autism and FASD. Following the recommendations for mixed methods designs outlined by Teddlie and Tashakkori (2009), this study integrated qualitative research (collected in a semi-structured interview by the investigators) and quantitative research (as measured by two psychometric measures listed below). Mixed methodologies enrich research findings by supplementing results of either methodology by integrating both thematic and statistical data, resulting in a more comprehensive understanding of the research results (Teddlie & Tashakkori, 2009).

## Participants

Families were accessed as part of a larger study through disability support organizations throughout Ontario, Canada. Respondent-driven sampling was also used, whereby individuals known by the researcher were contacted in search of families who might be interested in participating in the study, and research participants referred potential participants to contact the first, second, or third author. Fifty-seven parents or guardians of children with FASD and 28 parents or guardians of children with autism responded to questionnaires, while 31 family members of individuals with FASD and 19 family members of children with autism participated in the interview component of the study. Participants included birth parents,

foster parents, adoptive parents, step-parents, and custodial grandparents. In order to participate, parents had to have at least one child with autism or FASD; total number of children with disabilities per family ranged from one to seven. See Table 1 for demographic information of the participants.

## Qualitative Interviews

Following a basic interpretive approach (Merriam, 2002), qualitative interviews were conducted with parents of children with autism and FASD. Interviews lasted between 45 minutes and 3 hours, blending more and less structured questions (Merriam, 2002), such as "When you see the future for your child, what do you see?" Interviews took place at the convenience of participants and in locations agreed upon by both the participant and the researchers, such as family homes and coffee shops. Follow-up questions were asked of the participants, using e-mail and telephone conversations. To ensure that the qualitative analysis accurately reflected the experience of participating families, the authors employed member-checking (participants were provided a summary of themes) and triangulation (comparison of multiple data sources, methods, and independent qualitative analyses conducted by the first, second, and third authors; Teddlie & Tashakkori, 2009). These strategies sought to provide a rich, thick description of the experience of families (Merriam, 2002) and notably all participants supported the conclusions made by the current authors.

## The Hope Scale

As the most commonly used dispositional measure of hope, this scale includes two subscales that measure both agency and pathways thinking. It is a self-report inventory consisting of 12 sentences designed for individuals over the age of 15. The sentences include four items to assess agency thinking (e.g., "I energetically pursue my goals"), four items to assess pathways thinking (e.g., "There are lots of ways around any problem"), and four distractor items (e.g., "I feel tired most of the time"). Participants were asked to rate each item using an 8-point Likert-type scale ranging from 1 (*definitely false*) to 8 (*definitely true*). This questionnaire is titled "The Future Scale" when

Table 1. Participant Demographic Characteristics

	FASD Group	ASD Group
<i>Demographic Characteristics</i>	(N = 57)	(N = 28)
Characteristics of mothers ( <i>n</i> )	42	19
Relationship to child with disability		
Biological <sup>a</sup> (%)	11.90	84.21
Step-parent (%)	4.76	10.53
Adoptive (%)	76.19	5.26
Foster (%)	7.14	-
Married and Common Law (%)	80.95	100.00
Characteristics of fathers ( <i>n</i> )	15	9
Relationship to child with disability		
Biological (%)	13.33	88.88
Adoptive (%)	73.33	11.11
Foster (%)	13.33	-
Married and Common Law (%)	93.33	100.00
Characteristics of children <sup>b</sup> ( <i>n</i> )	68	27
Gender (% male)	47.06	85.18
Average age (SD)	15.25 (7.50)	10.37 (5.49)
Ethnicity <sup>c</sup> (% Caucasian)	77.94	100.00
<sup>a</sup> biological relationship to child including grandmother and great-grandmother		
<sup>b</sup> all children diagnosed with the target disability from participating families		
<sup>c</sup> other ethnicity is First Nations		

administered to participants. Investigations of the Hope Scale's (Snyder et al., 1991) factor structure, reliability, and validity (including construct, convergent, and discriminant) have provided psychometric evidence supporting its use (Lopez, Snyder, & Teramoto Pedrotti, 2003; Snyder et al., 1991). The Hope Scale has also been used in past research exploring group differences (e.g., between high and low achieving college students, psychiatric patients, and veterans with Post Traumatic Stress Disorder; Crowson, Frueh, & Snyder, 2001; Snyder et al., 1991). In the only study to use the Hope Scale in a sample of parents of children with intellectual disabilities, the Cronbach's alpha coefficients reported for mothers' agency was 0.78 and pathways thinking was 0.73 and for fathers'

agency was 0.69 and pathways thinking was 0.80 (Lloyd & Hastings, 2009). When both parents completed the Hope Scale, an average family score was used in analysis because, from a statistical perspective, scores reported by mothers and fathers from one family are not representative of individual data points.

### **Questionnaire on Resources and Stress**

The Questionnaire on Resources and Stress, Friedrich's short form (QRS-F) (Friedrich, Greenberg, & Crnic, 1983) is a frequently used questionnaire designed to measure specific aspects of stress as experienced by families with a child with a disability. This 52-item self-report measure assesses four broad areas of stress:

(1) parent and family problems, (2) parental pessimism about their child's future, (3) child characteristics (problematic behaviours), and (4) physical incapacity of the child. The QRS-F uses a "true" or "false" format and asks parents to answer statements such as "Our family agrees on important matters." Data in the current study are analyzed following Honey, Hastings, and McConachie's (2005) recommendations of a 31-item QRS-F total stress score, for use in research with families of young children with autism. The 31-item QRS-F includes the parent and family problems and the parental pessimism subscales, and therefore addresses how a parent perceives their child. Honey and colleagues (2005) found that the physical and behavioural subscales of the QRS addressed the abilities/disabilities of the child, rather than the perceived experience of stress related to said abilities/disabilities. The researchers examined the reliability of the 31-item QRS-F and reported the Kuder-Richardson coefficients for mothers and fathers being .93 and .85 respectively (Honey et al., 2005). Full comparisons between families of children with autism or FASD on the QRS-F were presented in another paper (see Watson, Coons, & Hayes, 2013); therefore, the data presented here are based on individual items related to the future in order to enhance the qualitative findings. As with the Hope Scale, when more than one parent completed the QRS-F, an aggregated family score was used in analysis.

## Results

Interview transcripts and questionnaire data reveal that families of both children with FASD and autism have a great deal of concern for their child's future. When looking at the questions on the Pessimism scale of the QRS-F, which addresses doubt about the child's ability to achieve self-sufficiency, both participant groups expressed significant worry about the future. For example, 98% of parents of children with FASD and 80% of those with autism responded "true" to the question, "I worry about what will happen to \_\_\_\_\_ when I can no longer take care of him/her." Likewise, 93% of parents of children with FASD and 85% of parents of children with autism responded "true" to the similar question, "I often worry about what will happen to \_\_\_\_\_ when I can no longer take care of him/her." Finally,

98% of parents of children with FASD and 80% of parents of children with autism responded "true" to the question, "I worry about what will be done with \_\_\_\_\_ when he/she gets older." In order to assess if there was a statistically significant difference between the responses of the autism and FASD family groups, independent-samples *t*-tests were conducted using PASW (18.0). When both parents completed the questionnaires, an aggregated family score was used (since mothers and fathers responses are not considered to be independent data points). Results of this analysis indicated that scores were not significantly different between the FASD or autism family groups on either the total 31-item QRS-F score or on any individual QRS-F item. However, the interview analysis that follows demonstrates that although families of both disability types may share some similar concerns, families of children with FASD and autism report unique hopes and worries for the future.

Interview data revealed that because of the large responsibilities they must bear, when asked about the future of their children, caregivers of children with FASD and those of children with autism said they both worry about what will happen to their child once they are no longer capable of supporting them. For example, Sarah, a biological grandmother to five granddaughters diagnosed with FASD, reflected on her role in her oldest granddaughter's future and stated "who's to say I'm going to be around when she's 20?" However, Denise, a biological grandmother to Hayley with FASD, preferred not to think about the future, saying, "I'm just kind of afraid of the future... I try not to think about the future." Likewise, Martha, a custodial grandmother to Johnny who has autism stated, "I just want to get... day by day... I, I, just, I can't imagine 10 years from now."

Although limited research has highlighted the concern and fear about their children's futures (e.g., Bilgin & Kucuk, 2010; Salmon, 2008) and the apprehension about lifelong parenting (e.g., Sanders & Buck, 2010) for these families, concerns and particular fears may vary according to the specific diagnosis of the child. In this study, parents of children with FASD and those of children with autism expressed several common and unique concerns related to their child's disability, which will be discussed further. Overall, interpretive phenomenological

analysis (IPA; Smith, Flowers, & Larkin, 2009; Storey, 2010) of interview transcripts revealed three main areas of concern: anxieties regarding level of independence, educational and vocational concerns, and fear of harm. Each theme will be discussed in turn and will be triangulated with supporting findings from the quantitative measures included (i.e., the QRS-F and Hope Scale).

### **Independence: “I would like to see him have a family and live on his own”**

This theme title, taken from an interview with Sara, a mother to Byron who is diagnosed with Asperger’s, demonstrates the preoccupation of parents with their children’s future living arrangements. Regardless of diagnosis, when asked about the future, parents discussed where their child would live in adulthood. Parents talked about whether or not they thought their children could live on their own or stay in the family home, and many family members talked about whether they would get married or have children. Parents’ beliefs about their child’s ability to live on their own were also reflected in their responses on the QRS-F. Particularly, 54% of parents of children with FASD compared to only 35% of parents of children with autism responded “true” to the question, “I have accepted the fact that \_\_\_\_\_ might have to live out his/her life in some special setting (e.g., institution or group home).” Although this difference was not found to be statistically significant, there were qualitative differences in how the two family types saw their child’s future independence.

### **Independence in Autism: “He’ll eventually be fully independent”**

Recognizing that autism is a spectrum disorder and therefore some children had greater support needs, most parents of children with autism felt their child would eventually live on their own with a bit of assistance. Only two parents of children with autism in this sample did not feel their children would leave their family home. Katrina stated, “I see no empty nest syndrome,” while Melanie, a mother to four sons with autism, when speaking about her oldest son Andre, whose symptoms are more severe than his siblings, affirmed, “I see

him at home. I can see him staying with us for a very, very long time.”

While Katrina and Melanie did not believe two of their children would achieve independence, most parents of children with autism were quite confident their child(ren) would live on their own. Vanessa, mother to twin girls with autism, stated, “I see them progressing well, you know, and I see us helping them along as much as we can.” All parents, regardless of their certainty in their child’s future independence, were concerned about how much help they will need to provide, whether it be by purchasing a second home for their child, paying their rent, or simply checking up on their child to make sure they have paid their bills or are taking their medications. As Melanie worried:

I keep thinking about where they’re going to live, how they’re gonna pay for it... I always have visions of me supporting them for as long as possible you know, trying to get them set up, or, do I have to buy them a house so at least they’ll have somewhere to live, will I have to worry about that every month.

Parents discussed how they are working with their children to develop greater safety skills and how they are leaving their children alone for short periods of time. Matt, father to Michael with autism, discussed, “I think he’ll probably live with us for a while. I think eventually he’ll be able to live by himself. I think ... I’ll have to call him every day to remind him to do things. Have you paid your phone bill, son?” The words of parents of children with autism captured the reciprocal nature of hope, as they described the potential for positive and independent lives (agency) while acknowledging that they as parents will need to play an active role in helping them attain those goals (pathways).

### **Lack of Independence in FASD: “I can’t imagine her ever living on her own”**

While most parents of children with autism hoped for their child’s future independence, parents and caregivers of children with FASD acknowledged the lifelong challenges that interfere with their children’s ability to live an independent adult life. In fact, most parents believe that their child(ren) will be unable to

live without the assistance of a friend, mentor, or caregiver. Karen, a foster mother to a son with FASD, admitted, "Patrick can never live on his own. Never. He needs structure, he needs support, he needs someone to connect the dots for him... I don't even know how he'd survive." Emily, an adoptive mother, worried that without assistance her daughter will end up homeless: "I fear that Lisa's going to be one of these women that you see on the streets when she's 30, and she's 40, and she's 50." Faith hopes that her adoptive daughter Grace will find structure and support in a spouse. "We're hoping she gets a husband that will take care of her." In contrast to families of children with autism, families of children with FASD did not speak with hope about the potential for their child(ren) to live independently.

**Marriage and Family: "I hope that he has a positive relationship with a woman... may or [may] not have a family"**

Sara, mother to Byron, articulated the sub-theme title and recognized that her hopes may be ideal, but she was not alone in her thinking. Many parents of children with autism and FASD spoke about their hope of one day seeing their children getting married and having children of their own. Some parents of children with autism spoke with hope about grandchildren, such as Carl, who talked about his son Caleb, "I see him married, I see him with kids, I think he's going to be an awesome Dad, because ... his forte is young kids, he excels when there's a young child nearby ... they attract to him like bees on honey." Others like Kelly worried that her son Ken with autism will be alone, "I still have concerns about his future ... and will he find somebody? 'Cause he often says oh, I'd like a girlfriend, and things like that are still heartbreaking, but he's happy, and I mean that's all you could ask for, you know?" Families of children with autism appeared to have a greater sense of agency with regards to their child's ability to marry and have children, and yet questioned if they would have the opportunities, or pathways thinking, to find a future partner.

Unlike many parents of children with autism who are fairly hopeful about the prospect of

having grandchildren, all of the parents of children with FASD were much more apprehensive. Many caregivers worried about teenage pregnancy. Natalie, an adoptive mother of two daughters with FASD, offered a candid view of one of her daughter's future, stating, "My honest, honest opinion is I probably think she'll be pregnant by the time she's 17." Sarah shared the same fear for her granddaughter: "I don't want her with 6 or 7 kids when she's 20, I don't want them all to have different fathers, either." Many parents worried that teenage pregnancy would further compound the challenge of independent living, questioning whether their child would have the ability to take care of himself or herself, let alone a child of their own. In fact, of the families that participated in this study, five daughters with FASD had been pregnant in their teens, with two daughters becoming pregnant as early as twelve years of age. Of these five daughters who had been pregnant, three had multiple pregnancies. Parents of children with FASD again spoke with less hope and were more pessimistic about their feelings of efficacy (agency) and ability to overcome obstacles (pathways) when helping their child(ren) navigate the future.

**Education and Employment: "I worry that there's employers who won't have an understanding"**

When asked about the future, parents of children with autism and FASD also spoke about vocational and educational expectations. Both groups of parents were concerned that there will not be adequate supports in place to facilitate full inclusion in the community. The title of this theme came from an interview with Sharon, an adoptive mother to Cassandra with FASD. Likewise, Anna, mother to two sons both diagnosed with autism, worried:

I'd like for them to go to school and do what it is they want to do, and I worry about if they'll have supports to do, will they be able to do it? Will they let them in, you know, like he'd be an excellent engineer - but, you know, can he go through the process, even if he does, will he get a job, will they interview him, will they think he's weird - you know what I mean, like just whole - you know, will they be open enough?

For many parents of children with FASD, post-secondary education was not part of the expectations for the future of their children. For example, Kaylee, a teacher and adoptive mother of two children with FASD, shared her struggle to come to terms with the fact that her children will not be able to continue past high school:

[A]ll the other teachers are talking about their kids, you know, plans for university and college and so on and I'm thinking to myself at least my kid's not in jail today, you know, those kinds of things. So, you... I felt sort of ashamed, you know and, because you wanted more for your kids.

However, many parents, like Donna and Melanie, hoped their children would complete high school. Julie, a biological mother to two sons with FASD, was confident that her son Jonathan's future looked bright if he continued his education: "Proper education, I could see something happening for him. I'm not too sure what but...I could see something."

Parents of children with autism appeared to be more hopeful about their children's educational aspirations. For example, Matt was confident that "he's gonna go to school here [referring to the local University]. Like I'm convinced of that." Matt went on to talk about his son Michael finishing high school, "like actually finishing high school, not just going to high school for four years like a lot of special needs kids do. Like he will, he will get a graduation diploma... I really, honestly do."

When it comes to employment, parents of children with both FASD and autism seemed to set realistic expectations for their children. Natalie, for example, believed her adoptive daughter Elizabeth with FASD will be able to find fulfilling employment: "I don't think she'll probably be, you know, a doctor or a lawyer or anything like that, but she'll have a job. She'll have a job she likes, she'll be good at it." Conversely, Louis, a biological father, discussed how cognitive impairments, such as problems with attention and concentration, hinder his son's ability to work: "I can't see him holding down a job. He can't concentrate enough to hold down a job." In line with the qualitative findings, parents of both types of families responded "true" to the question "*\_\_\_\_\_ is limited in the kind of work he/she can do to make a living*" on the QRS-F. Statistically

there was no difference found between family groups, as 93% of parents of children with FASD and 75% of parents of children with autism agreed with the above statement.

Although they recognized their children's limitations, most parents of both children with FASD and autism believed that with realistic expectations and supports, their children would be able to find employment. Reflecting the reciprocal nature of hope, parents of both children with FASD and autism shared that with motivation (agency) and support (pathways), their child(ren) could find meaningful and appropriate employment. Sharon, an adoptive mother, believed that her daughter Cassandra with FASD would be able to work with the help of a supportive and understanding employer, but conceded that, "she'll always need someone who's sort of watching over her." Similarly, Jackie, mother to three children with autism, spoke of her daughter's future and believed, "I see her pursuing her dreams if we nudge them along realistically."

Parents of children with autism in particular talked about future careers for their children that would complement their skills and sensitivities. Carla, mother to Evan, for example, talked about her son "going off to post-secondary and choosing a job where it will be more of an individual type career. Maybe computer something, uh, where he doesn't have to be as social, you know? It doesn't require to be around a lot of people all the time." Jackie, too, thought her son would take advantage of some of his autism-related behaviours and said, "I see Jack... doing something electronic, because he can manipulate any computer, any digital device you give him. So he might be a Mr. Fix it."

### **Harm: "You worry about them because you know kids are mean"**

Despite the hope expressed by many parents concerning education and employment for their children, caregivers also shared a more despondent view of the future. This theme title came from an interview with Kelly, mother to Ken with autism, who went on to say, "and you know that their life is gonna be harder." Parents of both children with FASD and autism were concerned about bullying, their children

getting in with the wrong crowd, and abuse in group homes. Several parents spoke about the “horror stories about group homes” and feared that if their child “falls into the wrong hands, I can see a cycle of abuse” (Jackie, mother to three children with autism). Despite some common concerns, fear of future harm was much more salient in interviews with families of children with FASD than with families of children with autism.

### **Fear of Harm in FASD: “I see him sitting in a jail cell”**

As Annie, a foster mother, puts it, “Well, I guess, back about ten, twelve years ago, maybe a little bit more than that, the only future I could see for him was he was gonna wind up out on the street, or in jail, or dead very early.” Furthermore, she added, “I can remember... having to accept that he would most likely die before us.” These statements highlight an important reality for many parents of children with FASD, who fear that their child’s naïve trust of others, combined with their difficulties understanding social cues and linking actions to consequences, would ultimately lead them to an early death. Karen, a foster mother, discussed her fears for her son Stephen:

If you look back in the papers and that, even the ones well protected died because the one time that child got out, they’re so trusting they don’t, they can’t, um, read a lot of social cues so they go, they’ll go get in trouble, get in a fight, get stabbed, get someone’s face, get in their face, you know, not know when to back off. Um, they get into drugs so easily ‘cause they’re lead astray so easily. They don’t have that sense that comes into factor.

For other parents, their child’s future contained only one likely outcome: “Jail.” This one-word response was spoken by Barbara, a biological mother, who believed her son Austin would end up incarcerated. Similarly, Louis, a biological father, affirmed, “I see Pierre sitting in a jail cell.” Statistically, the likelihood that an individual with FASD will have trouble with the law is high, with an estimated 60% experiencing legal problems (Streissguth et al., 2004). In fact, the authors were struck by the candor with which parents disclosed during the interview that they believed their child would eventually

end up in jail. Moreover, some parents worried about the high potential for abuse, particularly in relationships. Gabrielle, an FASD educator and adoptive mother, worried that her adult daughter with FASD would be in a perpetual cycle of abusive relationships:

I see her very sad.... I see her as always, always wanting more love than she’ll ever get... And unless she goes for counselling, which she won’t, I think she’ll always pick people who are abusive. And always be sad and always empty and... Looking for something, and... So, the future is not very... Not what it could be, if somebody could help her.

### **Levels of Hope: “I’m Hoping, I’m Hoping...”**

Despite the similarity in scores on the Hope Scale between parent groups, findings from the QRS-F responses and interview transcripts captured differences in the level of hope parents felt regarding their children’s overall futures. Parents of children with autism appeared more hopeful and provided examples of both agency and pathways thinking while parents of children with FASD expressed more negative views of the future and shared fewer examples of agency or pathways thinking. Many parents of children with FASD worried that without their support, their child’s future would involve homelessness, jail, or even death. When parents of children with FASD were hopeful of their children’s futures, it was with less certainty and often relied on external factors such as finding the right partner, or support system. For example, Natalie, an adoptive mother stated, “I think she’ll be pretty independent. I think she’ll be... I think, like I said, once she’s got it she’s got it. And I think she’ll, she’s going to be okay. I think she’ll be okay.” On the other hand, parents of children with autism, were much more certain in their children’s future, as can be demonstrated by Ethan’s assertion, “I think he’s going to be a thriving part of society.” However, it is important to note that families of children with autism or FASD did not differ on their measured level of hope according to the Hope Scale (Snyder et al., 1991).

In order to compare hope between the autism and FASD family groups, independent-samples

*t*-tests were conducted. As previously described, when both parents completed the Hope Scale, an aggregated family score was used to capture family hope, agency, and pathways thinking. Results of this analysis are presented in Table 2. Based on Snyder and colleagues' (1991) definition of hope, there are no differences between the reported levels of agency, pathways thinking, or overall hope between families of children diagnosed with FASD or with autism.

An additional analysis was performed to see if any differences existed between the FASD and autism family groups controlling for the age of the children (e.g., families who had children who were over the age of 18 were omitted). Based on the qualitative findings presented above, it was speculated that parents and caregivers of children with FASD may have less reported hope as their children age due to the often bleak outcomes for adults with FASD (e.g., incarceration, early pregnancy, substance abuse). Results of this analysis are presented in

Table 3. Again, results of this analysis showed no statistically significant results for agency pathways, and overall hope between the families of children diagnosed with FASD or with autism. Consequently, differences between families of children with autism and those of children with FASD in this study were primarily qualitative in nature and results emphasize the subjective experience of parenting a child with a disability.

## Discussion

According to the definition of hope by Snyder and colleagues (1991), people with higher hope experience more positive emotions and life satisfaction, as well as less depression or anxiety (e.g., Arnau, et al., 2007; Chang, 2003; Lloyd & Hastings, 2009; Oettingen & Gollwitzer, 2002). Although measured hope did not differ between families of children with autism or FASD, the qualitative experience appeared to be distinct.

Table 2. Family Average Hope Scale Scores and Between Group Comparisons

Hope Scale	ASD Group			FASD Group			<i>df</i>	<i>t</i>	<i>p</i>	95% CI		Cohen's <i>d</i>
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>				LL	UL	
Agency	20	25.63	3.25	43	24.60	5.63	61	-.752	.455	-3.73	1.69	0.20
Pathways Thinking	20	25.50	2.45	43	25.38	4.81	61	-.102	.919	-2.40	2.16	0.03
Total Hope	20	51.13	5.20	43	49.99	9.77	61	-.487	.628	-5.79	3.52	0.13

*CI* = confidence interval; *LL* = lower limit; *UL* = upper limit

Table 3. Family Average Hope Scale Scores and Between Group Comparisons Excluding Families with Children over Age 18

Hope Scale	ASD Group			FASD Group			<i>df</i>	<i>t</i>	<i>p</i>	95% CI		Cohen's <i>d</i>
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>				LL	UL	
Agency	19	25.81	3.22	26	24.52	4.37	43	-1.093	.281	-3.69	1.09	0.32
Pathways Thinking	19	25.58	2.49	26	25.69	4.13	43	0.114	.910	-1.89	2.11	-0.03
Total Hope	19	51.39	5.19	26	50.21	7.85	43	-.571	.571	-5.36	2.99	0.17

*CI* = confidence interval; *LL* = lower limit; *UL* = upper limit

A qualitative analysis of interviews found that families of children with autism were hopeful when they spoke about future possibilities; that their children would be fully independent, educated, meaningfully employed, and married with children. They recognized that life may be harder, but hoped that the community would learn to better understand and accept them. The words of parents reflected the connection between feelings of agency and pathways thinking, where their enthusiasm for the strengths of their child(ren) in combination with the imagined future opportunities led to more hope for their futures. In contrast, qualitative analysis of interviews suggests that families of children with FASD recognized their lack of hope for their child's future, citing difficulties establishing independent living, education, employment, and significant positive relationships with peers and/or partners. Parents of children with FASD acknowledged that life might include jail, teen pregnancy, and other adversity. It appeared that parents of children with FASD spoke with less hope as they generally feel less successful (lower agency or motivation) and have fewer pathways available to them to overcome the challenges faced by child(ren) with FASD.

Families in this study were accessed in part using respondent-driven sampling, a recruitment method that uses social contacts among members of a population to recruit those who are hard to reach. Respondent-driven sampling has the potential to reveal a great deal about a population as a whole (Heckathorn, 1997; Heimer, 2005), such as the size of the recruiter's social network and the individuals who the recruiter may have approached, but who chose not to participate. However, a challenge of using respondent-driven sampling is that those with a very poor social network have a lower probability of being reached. Based on this information, it is possible to determine whether the sample is biased or unbiased and, if the sample is biased, the extent to which the sample varies from an unbiased sample (Heckathorn, 2002; Heimer, 2005). Inferences about the population as a whole are influenced by this chain of recruitment and cannot be ignored; therefore, it is important to consider how the use of respondent-driven sampling may have operated differently in both the FASD and autism groups.

Because this project is part of a larger mixed methods project, recruitment and data collection have been ongoing. For the FASD group in particular, active recruitment has been continuous for the past several years and more contacts have been made, leading to the recruitment of additional participants, which may in part explains the larger FASD sample. Furthermore, many parents of children with FASD expressed how important it was to participate in this study, as FASD is often misunderstood and under-researched. It is possible that families of children with FASD in our sample were more active in their recruitment of additional participants because of their personal feelings about the importance of the research. Although families of children with autism expressed similar remarks about the significance of the research, families of children with autism appeared to feel better supported by their communities and have also been more commonly represented in family research.

It is important to consider that differences between the two groups may contribute to the ways parents perceive the future. Families in the autism group have younger children, with ages ranging from 3 to 22 years of age (average age of 10.37), while children in the FASD group ranged from 4 to 36 years of age (average age of 15.25). It is possible that families of children with autism are more hopeful because they have more time to access the necessary support and services, ultimately improving the outcomes for their children. Furthermore, the teenage years appear to be particularly troublesome for children with FASD, with the emergence of problems such as trouble with the law and teenage pregnancy (Watson, Hayes, Coons, & Radford-Paz, 2013). Donna, an adoptive mother to two children with FASD, is more hopeful about her younger son's future, but remains apprehensive as he approaches his teenage years: "Um, I'm probably a little more optimistic for Erik's future but then, you know, he hasn't hit the teen years yet so we have to see how that goes." Furthermore, transitioning from the teenage years to the adult years can also be particularly challenging, since it is often viewed as a transition to "interdependence" rather than a transition to independence (Bennett, 2009). Many individuals may not be prepared for independence and there are often many deleterious outcomes, such as unemployment and incarceration, which families in this

study discussed. Many challenges faced by adolescents with FASD and their families continue into adulthood (Streissguth, 1997) and families may worry about money management, productive work, and safe living arrangements for their children, as was also seen in this study. However, even after excluding families that had children over the age of 18, the analysis still revealed no significant differences between the two family groups, indicating that the child's age may not matter in the perceived levels of hope for families of children with FASD or autism.

Family type may also play an important role in the perception of the future. The FASD sample was a heterogeneous group consisting of eight foster parents, 43 adoptive parents (32 mothers and 11 fathers), and 11 birth parents (8 mothers and 3 fathers), whereas the autism group was comprised of 23 birth parents (15 mothers and 8 fathers), one custodial grandmother, two step-mothers, and one adoptive family (Please see Table 1 for demographic information about the participants). Thus, inherent differences between adoptive/foster parents and birth parents of children with disabilities may impact hope for the future. Although this discrepancy is an issue, the family status is quite representative of children with FASD, where approximately 80% of children live in foster or adoptive homes (Astley, Bailey, Talbot, & Clarren, 2000). Paley and colleagues (2006) found that while all parents of children with FASD reported high levels of parenting stress, adoptive and foster parents experienced stress related to their child's difficult behaviours, whereas biological parents reported increased stress associated with the parenting role, such as the perception of parenting competence and problems with parents' health and mood. The experience of stress, which is different for each family type, may in turn influence the way parents perceive their children's future.

Conversely, it is possible that there is something unique about FASD that leads to less qualitative hope. An important protective factor that has been found to mitigate the effects of secondary disabilities in FASD is living in a stable, nurturing home (Streissguth et al., 2004). However, stability and nurturance may not be possible for children who live in multiple foster homes throughout childhood. Such transitions may

lead to the presence of more secondary disabilities, such as problems with mental health, legal trouble, and challenges with education and/or employment. The relationship between the severity of secondary disabilities and hope for the future requires further investigation.

Another potential explanation for the differences we see between these two types of families may stem from their belief and hope for a treatment option. Intensive Behavioural Intervention (IBI) is considered best practice treatment for autism (Perry et al., 2008), and thus parents of children with autism often pursue IBI treatment to enrich their child's early development, as well as to ameliorate challenging behaviours and prevent the intensification of behaviour difficulties later in life. Additionally, although complementary and alternative forms of medicine have yet to be demonstrated as effective scientific treatment possibilities for autism, some parents turn to using these forms of treatment when conventional medicine is unsuccessful. For example, Harrington, Patrick, Edwards, and Brand (2006) found that the majority of parents in their study reported using at least one alternative medicine treatment for their child's autism, with a median number of six different treatment methods attempted, including dietary restrictions such as gluten- and casein-free diets, dietary supplements, and herbal medications.

Although parents of children with autism are presented with a variety of potential treatment options, parents of children with FASD unfortunately do not have the same options or hopes for effective treatment. Because prenatal exposure to alcohol causes organic brain damage and is a serious, lifelong disability (Chandrasena, Mukherjee, & Turk, 2009; Olson, Jirikowic, Kartin, & Astley, 2007), there are few treatment options available for individuals with FASD. Commonly, interventions designed for other disabilities have been applied to individuals with FASD and it is only recently that treatments are being specifically designed and evaluated that target FASD (Bertrand, 2009). Intervention and "treatment" choices for FASD have traditionally focused mainly on the initial prevention of the disability (Barry et al., 2009; Caley, Kramer, & Robinson, 2005; Nguyen, Coppens, & Riley, 2011), as well as the prevention and management of secondary disabilities

(Burd, 2006). Although new interventions are emerging, they do not yet have widespread availability. Consequently, parents may have less hope because there are very few accessible, specific treatments or intervention programs for FASD behaviours.

Without any prompting, five caregivers of children with FASD brought up the difference between autism and FASD. As Celine, mother to Anthony and Manfred lamented:

... you know, it's a neurological disorder. Kids with autism have a neurological disorder, but look how much they do for the kids with autism. Why don't they do the same for kids with FAS? ... they're both neurological disorders, why not? I know a friend who has a kid with autism and he has... a [speech language pathologist] with him. Every day, all day long. And that's what [my son] needs.

Similarly, Karen stated, "the only reason Patrick has a [classroom] support right now is there's a little boy with autism in his class, so she's helping both of them." Parents of children with FASD appear to feel like their children are forgotten. Marc, a foster father to several children with FASD over the years bemoaned, "they've got all kinds of monies for the other types of children, but they're really forgetting about the Fetal Alcohol Syndrome spectrum."

Awareness and research support between FASD and autism appears to be a striking difference that contributed to family's level of hope and thoughts for the future. For example, Veronica, an adoptive mother to Irene with FASD, referred to her frustration with the lack of awareness of FASD: "You know, autism is recognized, Down's [syndrome] is recognized, everything else is recognized except for this [FASD]. And I think that's what's frustrating and just trying to think of how do you go about to get them to recognize?" While parents of children with FASD reported significant fears for the future of their children, because of the amount of autism awareness, many parents of children with autism were hopeful for a "cure." Matt, father to Michael, who has autism, demonstrates this hope in a quote:

A lot of money is being tossed at this. I think there will be some understanding of the chemical basis of this so I think within his lifetime, I think

there will be a lot more control of it... it could be gene therapy, it could be some sort of biochemical thing...

Such faith in the research conducted might be what contributed to more hopeful responses by parents of children with autism.

In conclusion, parents of children with either FASD or autism living in Ontario face unique challenges related to both the special needs of their children. Although they did not differ on a quantitative measure of hope, they reported distinctive qualitative experiences when speaking about their future expectations for their children. Families of children with autism believed that, despite life potentially being harder for them, their children could live fully independently, hold meaningful employment, and have their own families in the future. Families of children with autism highlighted with hope that community awareness and acceptance will be an important factor that will contribute to their child's future full inclusion. In contrast, while families of children with FASD reported being hopeful individuals, they also cited having a lack of hope for their child's future. Parents of children with FASD recognized that their children will have more difficulties gaining independent lives, employment or an education, or establishing healthy, positive relationships. Future outcomes expected by families of children with FASD highlighted the secondary disabilities associated with this diagnosis, and included incarceration, unplanned teen pregnancies, vulnerability to victimization, early school leaving, and other adversity.

Given the high prevalence of FASD, as professionals it therefore becomes imperative that we continue to investigate and make evidence-based interventions accessible to families of children with FASD. Such investigations and supports will permit families of children with FASD to no longer feel as though families of children with autism are the only ones with access to hopeful futures. Finally, mixed methods investigations such as this one that combined a strength-based measure (Hope Scale), a deficit-based measure (QRS-F), and a qualitative analysis of interviews, provide for a deeper understanding of the impact having a child with a disability may have on the fam-

ily. In contrast to traditional research focusing on the stressful impact of disabilities, the current study emphasizes that despite the stressors faced, families of children with FASD and autism are resilient and hopeful.

## Key Messages From This Article

**People with disabilities:** Parents of children with FASD and autism worry about the future of their children, but they also have hope.

**Professionals:** Increased community awareness and accessibility to effective interventions are important contributors to families' levels of hope for the future.

**Policymakers:** There is a need for more specific and evidence-based supports to promote a sense of hope for families of children with FASD.

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