

Family Quality of Life and ASD: The Role of Child Adaptive Functioning and Behavior Problems

Emily Gardiner and Grace Iarocci

The family is the key support network for children with autism spectrum disorder (ASD), in many cases into adulthood. The Family Quality of Life (FQOL) construct encompasses family satisfaction with both internal and external dynamics, as well as support availability. Therefore, although these families face considerable risk in raising a child with a disability, the FQOL outcome is conceptualized as representative of a continuum of family adaptation. This study examined the role of child characteristics, including adaptive functioning and behaviour problems, in relation to FQOL. Eighty-four caregivers of children and adolescents (range = 6–18 years) with ASD participated, completing questionnaires online and by telephone. Adaptive functioning, and specifically daily living skills, emerged as a significant predictor of FQOL satisfaction, after accounting for behavioural and demographic characteristics, including child age, gender, perceived disability severity, and behavioural problems, as well as family income. Furthermore, there were significant differences across each domain of FQOL when groups were separated by daily living skill functioning level ('low,' 'moderately low,' and 'adequate'). The results suggest that intervention strategies targeting daily living skills will likely have beneficial effects for both individual and family well-being, and may reduce family support demands. *Autism Res* 2015, 8: 199–213. © 2015 International Society for Autism Research, Wiley Periodicals, Inc.

Keywords: Family Quality of Life; autism spectrum disorder; adaptive functioning; behavior problems

Introduction

Autism spectrum disorder (ASD) impacts the lives of those affected, yet the impact of ASD on the family may be particularly significant. The family acts as the key support network for the child with ASD, in many cases well into adulthood. The family unit must collectively work to negotiate around the many challenges associated with supporting the affected individual. Having a child with ASD is often conceptualized as a risk factor in terms of family well-being, as there is additional stress placed on family relationships (i.e., among spouse, parent–child, and sibling interactions), as well as on family member's roles and responsibilities [Gardiner & Iarocci, 2012; Gau et al., 2012; Petalas, Hastings, Nash, Hall, Joannidi, & Dowey, 2012]. Moreover, families are often navigating within previously uncharted territory, and must seek information about diagnosis, atypical developmental trajectories, intervention approaches, all while coming to terms with their altered expectations for their child [Bayat, 2007; Iarocci, Virji-Babul, & Reebye, 2006; Nissenbaum, Tollefson, & Reese, 2002]. Indeed, previous research has predominantly focused on such outcomes of parental dysfunction, examining individual indicators such as stress,

perceptions of burden, and poor mental health. In more recent years, the Family Quality of Life (FQOL) construct, which aims to consider the broader spectrum of family outcome, has emerged. This perspective permits a family-focused orientation, and extends from a rich body of literature examining Quality of Life (QOL) for individuals with disabilities [Schalock et al., 2002]. FQOL is defined as “conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them” [Park et al., 2003, p. 368]. It is “collectively and subjectively defined and informed by its members in which individual and family-level needs interact” [Zuna, Summers, Turnbull, Hu, & Xu, 2010, p. 262]. FQOL research is based on a strong theoretical model [Zuna et al., 2010], and is more consistently defined than other constructs, such as family well-being, adaptation, or functioning, which have at times suggested that the absence of parental dysfunction (i.e., clinically significant depression) signifies positive well-being [Turnbull, Summers, Lee, & Kyzar, 2007]. Moreover, the most commonly utilized measures, the Beach Center Family Quality of Life Scale [Hoffman, Marquis, Poston, Summers, & Turnbull, 2006] and Family Quality of Life Survey 2006 [Brown

From the Department of Psychology, Simon Fraser University, Burnaby, BC, Canada V5A 1S6 (E.G., G.I.)

Received August 08, 2014; accepted for publication November 25, 2014

Address for correspondence and reprints: Emily Gardiner, Department of Pediatrics, University of British Columbia, Vancouver, BC.

E-mail: emily.gardiner@cw.bc.ca

Published online 29 January 2015 in Wiley Online Library (wileyonlinelibrary.com)

DOI: 10.1002/aur.1442

© 2015 International Society for Autism Research, Wiley Periodicals, Inc.

et al., 2006a], were developed with key stakeholders, and intended specifically for families of individuals with disabilities, thereby ensuring their multidimensionality is focused on those domains most relevant to these families' lives. This is in contrast to the other areas of research that more commonly utilize tools not originally intended for disability populations, such as the Centre for Epidemiological Studies Depression Scale [Radloff, 1977; Turnbull et al., 2007]. FQOL takes a multidimensional approach to studying family outcomes, encompassing family satisfaction with both internal and external dynamics and resources, such as cohesive family interactions and preparedness to support their children's needs, as well as availability of external supports, both formal and informal. Therefore, although these families face considerable risk in raising a child with a disability, the FQOL outcome is conceptualized as representative of a continuum of family adaptation [Gardiner & Iarocci, 2012].

With regard to FQOL measurement, a caregiver typically reports on the satisfaction of the family across a number of domains that reference different aspects of family life, and all items, with the exception of those related to supports for the individual with a disability, inquire about the family unit. Respondents must, therefore, reflect on more than just their own perspective, and consider that of the collective family. Research indicates that respondents report different levels of satisfaction when reporting on their own QOL, as opposed to FQOL [Brown, MacAdam-Crisp, Wang, & Iarocci, 2006b].

Most of what we know about FQOL is based on studies of heterogeneous samples of children with intellectual and/or developmental disabilities. Although this work builds important knowledge about how FQOL processes interact at a broad level, the diverse behavioral and functional profiles of varied diagnoses may differentially impact FQOL. This is supported by recent studies, which identify that families of children with ASD are the least satisfied with their QOL, as compared to families of typically developing children, and to families of children with other neurodevelopmental disorders [NDDs; Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2014], such as Down syndrome [Brown et al., 2006b] and attention-deficit/hyperactivity disorder [ADHD; Lee, Harrington, Louie, & Newschaffer, 2008]. This underscores the considerable, and perhaps unique risk facing families of children with ASD, and supports the need to explore determinants of QOL within this group. Efforts to focus on FQOL in ASD specifically are beginning, with two studies investigating specific child and family characteristics. Pozo, Sarriá, & Brioso [2014] found that ASD symptom severity was a significant predictor of families' QOL satisfaction ratings. They also found that child behavior problems were related to FQOL, however, indirectly through caregivers' sense of

coherence, defined as the extent to which mothers viewed their life as comprehensible, manageable, and meaningful. As such, it was the feelings of uncertainty accompanying their child's behavior problems that directly predicted FQOL. McStay, Trembath, & Dissanayake [2014] also identified behavior problems and family sense of coherence as important variables for FQOL, as both were unique predictors of mothers' and fathers' satisfaction ratings. Coping also emerged as significant for mothers. This study, however, did not use the same statistical techniques as Pozo et al. [2014] and as such did not examine direct vs. indirect effects.

It is important to consider additional circumstances that place these families at risk. One risk factor may be the distinct behavioral profile demonstrated by those with ASD. In comparison to individuals with other NDDs, those with ASD, both with and without comorbid intellectual impairment, demonstrate a specific behavioral profile characterized by impaired adaptive functioning and the presence of problem behaviors [Lecavalier, 2006]. Much of the family research exploring these ASD-characteristic behaviors, however, has examined behavior problems without also considering adaptive functioning. Although the former has been shown to be stable over a one-year period [Lecavalier, Leone, & Wiltz, 2006], the acts themselves can be construed as acute, as they may arise in response to various antecedents and are related to aspects of the environment [Allen, 2009]. Adaptive functioning is defined as "the performance of daily activities required for personal and social sufficiency" [Sparrow, Cicchetti, & Balla, 2005, p. 6], and is measured by the extent to which an individual independently executes developmentally appropriate communication, socialization, daily living, and motor skills. Individuals with ASD are typically impaired in all domains; however, they demonstrate the greatest deficits in socialization, and this distinct profile is consistent across those with and without intellectual impairment [Sparrow et al., 2005]. Although intelligence is strongly correlated with and predictive of adaptive functioning, those with low IQ (i.e., intelligence quotient [IQ] < 70) demonstrate the opposite pattern to those whose intelligence is higher (IQ > 70). Adaptive behavior composite (ABC) scores are higher than IQ in those with intellectual impairment, whereas for those with higher intellectual abilities, adaptive behavior scores are lower than IQ [Kanne, Gerber, Quirnbach, Sparrow, Cicchetti, & Saulnier, 2011; Perry, Flanagan, Dunn Geier, & Freeman, 2009]. The impact of adaptive functioning, however, on parental outcomes is often only considered in lower functioning children, though such deficits are not specific to those with intellectual impairment.

"Adaptive functioning," therefore, encompasses abilities that are inherent in navigating virtually every

aspect of daily life, and scores reflect the extent to which individuals are able to independently complete associated tasks. Low scores, as observed in those with ASD, indicate that these individuals require significant help across domains, such as in personal care and with coping, and that they have great difficulty communicating their needs and understanding those around them. As such, adaptive functioning impairments could be conceptualized as chronic and pervasive in nature. These deficits are also enduring, and they become more significant with age. For example, although adaptive deficits are present in those with ASD in the early years as compared to peers with other NDDs, the discrepancy between chronological age and adaptive abilities actually widens over time [Paul, Loomis, & Chawarska, 2014; Perry et al., 2009]. Research demonstrates that with increasing age, individuals with ASD are less able to demonstrate developmentally appropriate adaptive skills in comparison to their same-aged TD peers, and these children and adolescents must increasingly rely on others for support [Kanne et al., 2011; Klin, Saulnier, Sparrow, Cicchetti, Volkmar, & Lord, 2007]. It is likely that the necessary support comes primarily from family members, yet little is known about the relations between these child characteristics in terms of family outcomes, or how the family may be affected by the interaction of behavior problems across different levels of child functioning.

Research on adaptive functioning and behavior problems is predominantly focused on outcomes of parental stress or burden and has produced mixed results. For example, Tomanik, Harris, & Hawkins [2004] found that both problem behavior and adaptive functioning were predictive of parental distress, and the authors suggested that the two variables are inversely associated, such that poorer adaptive functioning is associated with greater problem behaviors. Fitzgerald, Birkbeck, & Matthews [2002] found that both dependency on others for self-care and maladaptive behavior were significantly and positively related to family burden, indicating that as self-care support needs and behavior problems increased, so did the perceived level of burden. In contrast, Estes, Munson, Dawson, Koehler, Zhou, & Abbott, [2009], Estes et al. [2013] found that adaptive functioning was not a significant predictor of parenting stress or psychological distress. This research, however, was conducted with toddlers and preschool-aged children, whose adaptive functioning may be less impaired in comparison to peers [Kanne et al., 2011]. Moreover, Estes et al. [2009, 2013] looked only at the daily living skills domain. How socialization and communication, both of which are hallmark areas of impairment for those with ASD, influence parental outcomes remains unclear.

In this study, we examined how a key characteristic of the ASD behavioral profile, adaptive functioning, con-

tributes to FQOL, while taking into account behavior problems and demographic variables, including family income and disability severity, both of which have been shown to significantly predict FQOL [Hu, Wang, & Fei, 2012; Wang et al., 2004]. Adaptive functioning was conceptualized as more chronic and impactful on the family than behavior problems. Adaptive function deficits are also more common across those with ASD than are behavior problems [Kanne et al., 2011; Lecavalier, 2006], and the latter are more related to parental and family outcomes in those with developmental delay [Estes et al., 2009; Pozo et al., 2014]. Using a well-characterized sample, in which comprehensive adaptive and behavioral information was collected, we were able to clarify the relations among these child characteristics and FQOL without confusing their impact with intellectual disability (ID)-associated impairments. This was important as a recently published study demonstrated that different mechanisms contribute to burden in families of children with ASD with and without intellectual impairment [Vogan, Lake, Weiss, Robinson, Tint, & Lunsby, 2014]. This underscores the importance of understanding the functioning level of children with ASD when considering family outcomes, and of differentiating between those with and those without intellectual disability. Furthermore, we included three domains of adaptive functioning in relation to FQOL, as opposed to only the composite score. It was expected that this would provide greater insight into the relative contribution of each skill domain, and explain greater variance in the outcome than would the composite measure alone. Given the uneven adaptive profile observed in this population (i.e., relatively low socialization), it is possible that these meaningful discrepancies would be lost in an index that averages across domains. Moreover, it was expected that examining adaptive functioning in this way would better lend itself to practical recommendations, which is a key goal of FQOL research [Isaacs et al., 2007]. This work addressed two research questions:

1. Does child adaptive functioning predict FQOL satisfaction after controlling for behavior problems and demographic variables?
2. Is there a statistically significant effect of adaptive level (low, moderately low, adequate) on FQOL when examined by domain (e.g., family interaction, parenting, emotional well-being, etc.)?

Methods

Participants

Eighty-four caregivers of children with ASD between the ages of 6 and 18 years (inclusive) participated in the study, most (89.3%) of whom were mothers. All

participating families were recipients of the provincial Autism Funding: Ages 6–18 program that provides up to \$6000 for eligible out-of-school intervention services, and the child age range was chosen to keep the amount of provincial autism funding consistent across families. This study is part of a larger mixed-methods project, one of the aims of which was to examine families' experiences with service delivery. As such, it was important to ensure that participants were navigating within the same service context, so specific recommendations could be made. Families represented a range of ethnicities and most (94.0%) respondents indicated that English was their family's primary language, though 31% indicated that at least one other language was also spoken at home. Respondents ranged in age from 30 to 65 years ($M = 44.5$, $SD = 6.39$). The median family income reported was \$80,000–\$109,999, which is somewhat higher than the national (\$72,240) and provincial (\$69,150) medians [Statistics Canada, 2013]. It was not higher, however, than that reported within other FQOL research [e.g., Hu et al., 2012]. Most (71.4%) families resided within the province's largest regional district, with the remaining individuals coming from 27 cities across 11 regional districts. Most (78.6%) families had multiple children, with two being the most common (range = 1–4), and 20.2% had multiple children with disabilities. Of these families, most (70.6%) had two children with disabilities (range = 1–3), and the most common sibling diagnosis was ASD. Other sibling diagnoses included ADHD, ID, and Tourette's disorder. See Table 1 for family demographic characteristics.

To facilitate the research aim of examining the impact of adaptive functioning on FQOL, and not confound with ID-associated impairments, the study inclusion criteria dictated that caregivers' children with ASD be between the ages of 6 and 18 years (inclusive) and not have a comorbid ID (based on caregiver report). If participants had more than one child who fit these criteria, they were asked to focus on the child who exerted the most impact on their family, as indicated by Rillotta, Kirby, & Shearer [2010]. On average, children with ASD were 11.5 years of age ($SD = 3.68$). The male to female ratio was found to be 6:1. This is somewhat higher than is typically reported, as the prevalence ratio ranged from 3.6 to 5.1 (4.5 for all sites combined) in the most recent Centers for Disease Control and Prevention [2014] prevalence study. The most frequent age range during which children were diagnosed was between 2 and 4 years (39.2%) and most children (82.1%) were attending public school. Not surprisingly, caregivers' ratings of their children's intellectual functioning were slightly negatively skewed with "high average" being the most frequent rating, whereas they were positively skewed for social functioning (most rated their child's social func-

tioning as "low average"). This is consistent with both the study's inclusion criteria (i.e., no ID) and disorder characteristics (i.e., social impairment). As expected, almost all (95.2%) caregivers reported that their children had at least one "other condition" aside from ASD, most frequently (26.2%) endorsing three additional conditions (range = 0–10). The most frequently reported conditions included mood/expression/anxiety problems (61.9%), behavioral problems (45.2%), general problems with motor control/coordination (34.5%), and sensory integration impairment (34.5%). See Table 2 for child demographic characteristics.

Diagnostic Confirmation

Participating caregivers' children received a standardized clinical diagnosis of ASD from a qualified paediatrician, psychologist, or psychiatrist associated with the provincial government-funded autism assessment network, or through a qualified private clinician. All diagnoses were based on the Diagnostic and Statistical Manual of Mental Disorders [DSM; APA, 2000, 2013] and confirmed using the Autism Diagnostic Interview—Revised [ADI-R; Rutter, Le Couteur, & Lord, 2008] and Autism Diagnostic Observation Schedule [ADOS; Lord, Rutter, DiLavore, & Risi, 1999], both of which are gold standard tools of ASD diagnostic assessment. As the ASD diagnosis is tied directly to substantial provincial funding programs, British Columbia has instituted standardized diagnostic practices. All individuals are required to be diagnosed by ADOS- and ADI-R-trained clinicians who use these tools and clinical judgment to make the diagnosis. This also pertains to individuals who have been diagnosed in a different province or country, as they are required to be rediagnosed on their arrival to British Columbia using these practices. The children of participants in this study were diagnosed using these standardized diagnostic practices.

The Social Communication Questionnaire—Lifetime version [SCQ; Rutter, Bailey, & Lord, 2003], a screening tool, was also used to determine whether participants' children had developmental histories consistent with ASD. The SCQ consists of 40 yes-or-no questions, taken from the ADI-R [Rutter et al., 2008], that focus on communication skills and social functioning. A total score is provided that identifies individuals who may have ASD based on a specified cut-off point (≥ 15 for ASD). The ASD cut-off has strong sensitivity (85%) and specificity (75%), and the correlation between the SCQ and ADI-R was 0.78. Test–retest reliability, as measured 12–24 months apart, was 0.74 [Naglieri & Chambers, 2009]. Internal consistency, as measured by Cronbach's alpha was 0.85 in this study. Fourteen children did not meet the ASD cutoff, and sensitivity was, therefore, 83.3%. As this rate is consistent with that cited in the

Table 1. Family Demographic Characteristics

Demographic information	<i>n</i> (%)
Respondent relationship to child with ASD	
Mother	75 (89.3)
Father	8 (9.5)
Grandmother	1 (1.2)
Family ethnicity	
Canadian	34 (40.5)
Asian	12 (14.4)
European	13 (15.5)
Multiple	25 (29.8)
Primary caregiver age (years)	
30–39	21 (25.0)
40–49	48 (57.1)
50–59	14 (16.7)
60–69	1 (1.2)
Marital status	
Married or common law	64 (76.2)
Divorced or separated	12 (14.3)
Widowed	2 (2.4)
Never married	6 (7.1)
Maternal employment status	
Unemployed	2 (2.4)
Employed full-time	21 (25.0)
Employed part-time	33 (39.3)
Homemaker	17 (20.2)
Student	6 (7.1)
Other	5 (6.0)
Paternal employment status	
Unemployed	2 (2.4)
Employed full-time	64 (76.2)
Employed part-time	5 (6.0)
Homemaker	2 (2.4)
Other	11 (13.1)
Maternal level of education	
Elementary school	1 (1.2)
High school	9 (10.7)
Professional diploma	17 (20.2)
Undergraduate degree	32 (38.1)
Graduate degree	19 (22.6)
Other	6 (7.1)
Paternal level of education	
Elementary school	2 (2.4)
High school	19 (22.6)
Professional diploma	12 (14.3)
Undergraduate degree	24 (28.6)
Graduate degree	16 (19.0)
Other	11 (13.1)
Family income	
<\$20,000	5 (6.0)
\$21,000–\$49,999	14 (16.7)
\$50,000–\$79,999	15 (17.9)
\$80,000–\$109,999	21 (25.0)
\$110,000–\$139,999	13 (15.5)
\$140,000–\$169,999	5 (6.0)
>\$170,000	11 (13.1)
Multiple children with disabilities	
Yes	17 (20.2)
No	67 (79.8)
Sibling diagnoses	
ASD	13 (15.4)
Other NDD	9 (10.7)

Table 1. Continued

Demographic information	<i>n</i> (%)
Family member most responsible for child with ASD	
Mother	42 (50.0)
Father	4 (4.8)
Mother and father	17 (20.2)
Parents and siblings	16 (19.01)
Parents and other family members	1 (1.2)
Parents, siblings, and other members	4 (4.8)

Note. The “Asian” category under ethnicity included East Asian (e.g., Chinese, Japanese, *n* = 5), South Asian (e.g., Indian, *n* = 3), Southeast Asian (e.g., Filipino, Malaysian, *n* = 2), and West Asian (e.g., Arabian, Iranian, *n* = 2). The “Multiple” category included individuals who identified their families as representing more than one ethnicity (e.g., Aboriginal and European). “Other” employment included those who indicated they fell into multiple categories (*n* = 1), received disability funding (*n* = 4), were self-employed (*n* = 1), or reflected circumstances in which the particular parent was deceased or estranged (*n* = 8).

Table 2. Demographic Characteristics of Focal Child with ASD

Demographic information	<i>n</i> (%)
Age of child with ASD (years)	
6–12	54 (64.3)
13–18	30 (35.7)
Gender of child with ASD	
Male	72 (85.7)
Female	12 (14.3)
Child disability severity	
Mild	44 (52.4)
Moderate	32 (38.1)
Severe	7 (8.3)
Very severe	1 (1.2)
Intellectual functioning	
Low	4 (4.8)
Low average	15 (17.9)
Average	25 (29.8)
High average	31 (36.9)
Superior	9 (10.7)
Social functioning	
Low	29 (34.5)
Low average	47 (56.0)
Average	7 (8.3)
High average	1 (1.2)
Number of other conditions	
0–3	53 (63.1)
4–7	30 (35.7)
8–10	1 (1.2)

original validation sample [Berument, Rutter, Lord, Pickles, & Bailey, 1999] and with subsequent research examining SCQ properties [e.g., Chandler et al., 2007], these caregivers were retained in the final sample.

Measures

Adaptive Functioning

The Vineland Adaptive Behavior Scales, 2nd edition Survey Interview [Vineland-II; Sparrow et al., 2005] is a

383-item instrument designed to measure adaptive functioning in individuals aged birth-90 years across four domains: communication (e.g., how the child listens and what he/she says), daily living skills (e.g., how he/she eats and dresses), socialization (e.g., how he/she interacts with others), and motor skills (e.g., how he/she uses arms and legs for movement, and hands and fingers for manipulation; however, note that the latter domain is not administered for children aged 7 years and older). There are an additional 36 questions comprising the Maladaptive Behavior Index. Item responses are coded with a 3-point Likert-type scale ranging from "Usually" (2) to "Never" (0) based on behavior frequency. "Don't Know" is also a response option if the item refers to an activity occurring in an environment to which the respondent had no access (i.e., at school) and some questions include a "No Opportunity" response option, which may be chosen if referring to an activity that the child has no access to. Scores from the four domains (communication, daily living skills, socialization, and motor skills if applicable) are combined to provide an Adaptive Behavior Composite score. Standard scores ($M = 100$, $SD = 15$) are calculated for each domain. Higher scores on the adaptive behavior domains indicate better functioning, whereas higher scores on the maladaptive behavior index are indicative of greater impairment. Test-retest reliability, as measured 13–34 days apart, ranged from 0.74 to 0.94 across domains and composite scores [Sparrow et al., 2005]. In this study, Cronbach's alpha ranged from 0.93 to 0.97 on the adaptive domains and was 0.98 for the composite score. In this study, the Adaptive Behavior Composite, as well as socialization, communication, and daily living skills domain scores were utilized.

Behavior Problems

The Nisonger Child Behavior Rating Form—Parent Version [NCBRF; Aman, Tassé, Rojahn, & Hammer, 1996; Tassé, Aman, Hammer, & Rojahn, 1996] is a 76-item instrument measuring social competence (ten items) and problem behaviors (66 items) across eight subscales. Social competence subscales include compliant/calm and adaptive/social, and problem behavior subscales include conduct problems, insecure/anxious, hyperactive, self-injury/stereotypic, self-isolated/ritualistic, and overly sensitive. Respondents were asked to rate behaviors on a 4-point Likert-type scale. For the social competence scales, response options ranged from "not true" (0) to "completely or always true" (3), and behavior problem response options ranged from "did not occur or was not a problem" (0) to "occurred a lot or was a severe problem" (3). Subscale scores were calculated by summing ratings for domain-relevant items, and a total problem behavior score was calculated by

summing the 66 relevant items. Higher scores for the social competence items indicate that the child demonstrates more positive social behaviors, and higher scores for the problem behavior scales indicate more frequent and problematic behaviors. In this study, internal consistency for each subscale was found to range from 0.54 to 0.91 and was 0.95 for the total problem behaviors score. The values are consistent with those reported by Lecavalier, Aman, Hammer, Stoica, & Mathews [2004], although they reported higher consistency for the adaptive social and overly sensitive subscales than were found in this study (0.63 vs. 0.56 and 0.88 vs. 0.74, respectively). This measure has been used to assess behaviors in children up to 18 years [Lecavalier et al., 2006]. As the purpose of including this variable was to control for behavior problems, as opposed to examining specific issues related to such behaviors in children, the total problem behavior score, but not the separate subscale scores, was used in the analyses.

FQOL

The FQOL scale [Hoffman et al., 2006] assesses FQOL across five domains: family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support. This measure includes 25 questions with responses based on a five-point Likert scale ranging from "Very Dissatisfied" (1) to "Very Satisfied" (5). Domain scores were determined by calculating the mean rating of the domain-relevant items. An overall score was also calculated by averaging all item ratings. This instrument is internally consistent, and alpha values ranged from 0.74 to 0.86, and was 0.93 for the overall score in this study. Test-retest reliability for each subscale, as assessed 3 months apart, ranged from 0.60 to 0.77. The measure also included demographic questions about family income and disability severity. With regard to family income, the question included seven categories ranging from less than \$20,000 to more than \$170,000. The question regarding disability severity was the same scale as utilized by Hu et al. [2012] and Wang et al. [2004], and included four levels: mild, moderate, severe, and very severe.

Procedure

Caregivers participated in a telephone interview, during which they completed the SCQ and Vineland-II Survey Interview, and an online survey, in which they answered demographic questions and completed the NCBRF and FQOL scale. A small proportion ($n = 10$) of the participants indicated their preference for paper versions of the surveys, and completed the measures in this form. To assess whether this survey modality differentially influenced responses, two multivariate analyses

of variance (MANOVAs) were conducted with survey mode entered as a fixed factor and subscale and total scores for the NCBRF and FQOL, respectively, as dependent variables. The analyses revealed no group differences on the subscale or total scores (all $P > 0.10$). A subset ($n = 10$) was also randomly selected from those who completed the questionnaires online, and matched on age, gender, ethnicity, and education level to those who completed paper-and-pencil versions, as consistent with other research [Joubert & Kriek, 2009]. The same analyses were conducted, and the findings were consistent (all $P > 0.10$). This supports other research demonstrating the comparability of responses on paper-and-pencil as compared to online questionnaires [Fouladi, McCarthy, & Moller, 2002].

Results

All data analyses were conducted using SPSS Statistics, Version 22. The data were first converted to z-scores and screened for significant outliers, as well as for significant skew and kurtosis. One outlier was detected on the FQOL physical/material well-being subscale. As the subscale was critical to a planned analysis, the outlier was changed to the value of the next lowest score [Tabachnick & Fidell, 2013]. There were no significant deviations from normality.

Descriptive statistics for each measure are provided in Table 3. The average Vineland-II Adaptive Behavior Composite was in the “moderately low” range (71–85). Twenty-five participants had children classified as “adequate” (range = 86–104), 28 as “moderately low”, and 31 as “low” (range = 55–70). The range represented within the latter group is reflective of a “mild deficit” [Sparrow et al., 2005]. The “typical ASD profile” of relatively weak socialization scores in comparison to the communication and daily living skills domains was observed. The observed adaptive profile, including both the means and ranges, is consistent with research reporting on individuals with ASD of a similar age range (4–17 years) who have an IQ above 70 [Kanne et al., 2011]. Behavior problems, both total and by domain, were consistent with other studies with this population [Lecavalier, 2006; Lecavalier et al., 2006], with the exception of the insecure/anxious subscale, as the sample mean was somewhat higher than previously reported [Lecavalier, 2006]. Finally, the profile of FQOL domain scores, such that families reported being most satisfied with physical/material well-being and least with emotional well-being is consistent across research with families of children with ASD [Eskow, Pineles, & Summers, 2011], as well as other NDDs [Davis & Gavidia-Payne, 2009; Summers et al., 2007].

Table 3. Scale Descriptive Statistics

Scale	<i>M</i> (<i>SD</i>)	Observed range	Theoretical range
Vineland-II			
Adaptive behavior composite	77.56 (12.59)	55–104	20–160
Communication	81.18 (14.07)	54–120	20–160
Daily living skills	80.92 (14.32)	59–114	20–160
Socialization	75.82 (15.79)	31–114	20–160
NCBRF			
Compliant/calm	8.63 (3.08)	2–18	0–18
Adaptive social	5.63 (1.89)	1–11	0–12
Total problem behaviors	52.76 (25.05)	7–114	0–198
Conduct problem	11.43 (8.05)	0–35	0–48
Insecure/anxious	11.90 (7.43)	1–30	0–45
Hyperactive	10.27 (5.15)	1–22	0–27
Self-Injury/stereotypic	1.41 (2.05)	0–9	0–21
Self-Isolated/ritualistic	6.47 (4.03)	0–18	0–24
Overly sensitive	5.93 (3.00)	0–13	0–15
FQOL scale			
Overall	3.62 (.63)	1.68–4.76	1–5
Family interaction	3.81 (.75)	1.33–5.00	1–5
Parenting	3.61 (.72)	2.00–4.83	1–5
Emotional well-being	3.10 (.92)	1.00–4.50	1–5
Physical/material well-being	3.94 (.75)	1.60–5.00	1–5
Disability-related support	3.49 (.80)	1.25–5.00	1–5

Note. The reported Vineland-II statistics are standard scores. The NCBRF statistics are the summation of relevant items, and the FQOL Scale statistics are the mean of relevant item ratings. NCBRF = Nisonger Child Behavior Rating Form.

To answer the first research question (Does child adaptive functioning predict FQOL satisfaction after controlling for behavior problems and demographic variables?), we examined whether it was more appropriate to use the ABC score as a predictor, or to examine the relative contribution of each adaptive domain (communication, daily living, and socialization) individually. Given the uneven adaptive profile observed in those with ASD, we were concerned that utilizing a composite score would not reflect the very meaningful discrepancies present across such abilities in the sample. The utility of the Vineland-II ABC was first examined.

Adaptive Behavior Composite

Correlations were first examined among the predictors and FQOL satisfaction, and the per-test alpha level was set to 0.01 to reduce the chance of Type 1 error (see Table 4). Family income demonstrated a statistically significant and positive association with FQOL ($r = 0.33$, $P < 0.01$), such that higher reported family income was related to greater FQOL satisfaction. Adaptive behavior ($r = 0.43$, $P < 0.001$) was also significantly and positively related to FQOL, indicating that better adaptive functioning was associated with greater FQOL satisfaction. Conversely, problem behaviors demonstrated a significant inverse relation with FQOL ($r = -.47$, $P < 0.001$),

Table 4. Correlations Among FQOL, Demographic Variables, Behaviour Problems, and Adaptive Behaviour Composite

Predictor variables	1	2	3	4	5	6	7
1. FQOL	-	-.03	-.19	.33*	-.23	-.47**	.43**
2. Child gender		-	.04	-.30*	.00	.12	-.00
3. Child age			-	-.09	.12	.05	-.48**
4. Family income				-	-.14	-.29*	.26
5. Disability severity					-	.38**	-.27
6. Behaviour problems						-	-.48**
7. Adaptive functioning (ABC)							-

* $P < .01$; ** $P < .001$.

such that having children who exhibited greater behavior problems was associated with poorer satisfaction.

As all necessary assumptions were satisfied and the diagnostic statistics revealed no multivariate outliers or influential points, a hierarchical multiple regression analysis was conducted to examine the relations between child adaptive functioning, as measured by the ABC, and FQOL satisfaction. Child gender, age, and disability severity, as well as family income were accounted for in step 1, as previous research has demonstrated the significant relations between the latter two variables and FQOL [Hu et al., 2012; Wang et al., 2004]. Problem behaviors (NCBRF total score) was entered in step 2, and the Vineland-II ABC in step 3.

The first model, accounting for child gender, age, disability severity, and family income, was statistically significant, and accounted for 17% of the variance in FQOL satisfaction ($F(4, 79) = 4.05, P < 0.01$). The second model, with the addition of problem behaviors, was also statistically significant ($R^2 = 0.29, F(5, 78) = 6.39, P < 0.001$), and accounted for an additional 12.1% of the variance in FQOL satisfaction above and beyond model 1 ($\Delta F(1, 78) = 13.25, P < 0.001$). Although the third model, which added the ABC, was statistically significant ($R^2 = 0.31, F(6, 77) = 5.81, P < 0.001$), inclusion of the composite adaptive functioning predictor variable accounted for only an additional 2.1% of the variance in FQOL satisfaction above and beyond model 2 ($\Delta F(1, 77) = 2.34, P > 0.10$), and the associated regression coefficient did not make a significant contribution to the model ($P > 0.10$). Within model 3, only behavior problems was significant ($P < 0.05$), and accounted for an additional 5.9% of the variance in the model above and beyond the other predictors ($\Delta F(1, 77) = 6.64, P < 0.05$). The family income regression coefficient approached significance ($P = 0.05$). See Table 5 for a summary of the model at each step.

As adaptive functioning, as measured with the ABC, did not explain a statistically significant amount of variance in FQOL satisfaction, the relative contribution of

each adaptive domain (communication, daily living, and socialization) was then examined.

Adaptive Functioning Domains

To examine the relations among the predictor variables and FQOL satisfaction, correlations were examined. Again, the per-test alpha level was set at 0.01 to control for Type 1 error (see Table 6). Only newly identified statistically significant relations will be discussed here. Daily living ($r = 0.51, P < 0.001$) and socialization skills ($r = 0.37, P < 0.001$) were significantly and positively related to FQOL, indicating that better adaptive skills in these domains were associated with greater FQOL satisfaction.

As the necessary assumptions were satisfied, a hierarchical multiple regression analysis was conducted to examine the relations between the adaptive functioning domains and FQOL satisfaction. As with the previous analysis, child gender, age, and disability severity, as well as family income were accounted for in step 1, and problem behaviors (NCBRF total score) entered in step 2. In this analysis, however, the three adaptive functioning domains (communication, daily living skills, and socialization) were entered in step 3.

As the first two models are identical to the previous regression analysis conducted, only the results of model 3 will be described. The third model, which added the three adaptive functioning subscales of communication, daily living skills, and socialization, was statistically significant ($R^2 = 0.41, F(8, 75) = 6.47, P < 0.001$), and accounted for an additional 11.8% of the variance in FQOL satisfaction above and beyond model 2 ($\Delta F(3, 75) = 4.97, P < 0.01$). Within this model, family income ($P < 0.05$), problem behaviors ($P < 0.05$), and daily living skills ($P < 0.001$) were significant, and these variables, as a set, accounted for an additional 24.5% of the variance in the model above and beyond child gender, age, disability severity, and communication and socialization skills ($\Delta F(3, 75) = 10.35, P < 0.001$). Moreover, daily living skills accounted for an additional 10.4% of the variance in FQOL satisfaction above and beyond the other variables in the model ($\Delta F(1, 76) = 12.97, P < 0.01$). See Table 7 for a summary of the final model.

Finally, interaction terms (behavior problems \times adaptive functioning domains, age \times behavior problems, and age \times adaptive functioning domains) were included, one at a time, in step 4 of the model. As none of the examined interaction terms resulted in a statistically significant increase in explained FQOL variance, only the main effects were interpreted.

To address the second research question (Is there a statistically significant effect of adaptive level on FQOL when examined by domain?), a one-way MANOVA was conducted with daily living skill level (low, moderately low, adequate) entered as a fixed factor and satisfaction

with each FQOL domain as dependent variables. The daily living skills domain was chosen as the independent variable, as this adaptive domain emerged as most significant in terms of the impact on FQOL in the regression analysis. Using Pillai's trace, there was a significant effect of daily living skill level on FQOL domain satisfaction, $\lambda = 0.30$, $F(10, 156) = 2.80$, $P < 0.01$. Follow-up univariate ANOVAs [with an alpha level of 0.01 for each; Stevens, 2009] were then conducted on each FQOL domain. There was a significant effect of adaptive level on every FQOL domain, including parenting, $F(2, 81) = 11.63$, $P < 0.001$, $\eta^2 = 0.22$, emotional well-being, $F(2, 81) = 5.12$, $P < 0.01$, $\eta^2 = 0.11$, disability-related support, $F(2, 81) = 6.75$, $P < 0.01$, $\eta^2 = 0.14$, family interaction, $F(2,$

46.25) = 8.54, $P < 0.01$, $\omega^2 = 0.15$, and physical/material well-being, $F(2, 47.40) = 5.68$, $P < 0.01$, $\omega^2 = 0.10$.

Post hoc tests revealed that participants with children in the "low" daily living skill range had significantly lower FQOL satisfaction than those in the "adequate" range on family interaction ($P < 0.01$), parenting ($P < 0.001$), emotional well-being ($P < 0.05$), and disability-related support ($P < 0.05$). There were also significant differences between those in the "moderately low" and "adequate" ranges on family interaction ($P < 0.05$), parenting ($P < 0.01$), physical/material well-being ($P < 0.05$), and disability-related support ($P < 0.01$), with those in the "moderately low" group demonstrating lower satisfaction. There were no significant differences on any of the FQOL domains ($P > 0.05$) between those in the "low" and "moderately low" ranges, although it is interesting to note that those in the "low" group rated their satisfaction as slightly higher than those in the "moderately low" group on both physical/material well-being and disability-related support. See Table 8 for the FQOL domain satisfaction ratings across adaptive functioning level and Figure 1 for a visual representation.

Table 5. Hierarchical Multiple Regression Analysis Predicting FQOL Satisfaction from Demographic Variables, Behaviour Problems, and Adaptive Behaviour Composite

Predictor variable	B	SE B	β	P
Step 1				
Constant	3.57	.38		<.01
Child gender	.14	.19	.08	.49
Child age	-.02	.02	-.14	.18
Family income	.12	.04	.32	<.01
Disability severity	-.15	.09	-.17	.11
Step 2				
Constant	4.00	.37		<.01
Child gender	.17	.18	.09	.35
Child age	-.03	.02	-.15	.13
Family income	.09	.04	.23	.03
Disability severity	-.03	.09	-.03	.77
Behaviour problems	-.01	.00	-.39	<.01
Step 3				
Constant	3.01	.74		<.01
Child gender	.13	.18	.07	.46
Child age	-.01	.02	-.06	.59
Family income	.08	.04	.21	.05
Disability severity	-.02	.09	-.02	.82
Behaviour problems	-.01	.00	-.31	.01
Adaptive functioning (ABC)	.01	.01	.20	.13

Note. $R^2 = .17$ for Step 1, $\Delta R^2 = .12$ for Step 2, $\Delta R^2 = .02$ for Step 3.

Discussion

In this study, we examined the role of particular risk factors in QOL satisfaction among families of children and adolescents (aged 6–18 years) with ASD. As research to date has devoted less attention to the FQOL processes operating within specific NDD populations, and instead often examined the impact of particular child, family, and support characteristics with heterogeneous samples, this research focused on families of children with ASD. The unique adversity characterizing this circumstance is well documented, and the intent of this research was to investigate factors that contribute to these families' QOL. Specifically, we examined the impact of adaptive functioning, while taking important behavioral and demographic characteristics into account. This is the first

Table 6. Correlations Among FQOL, Demographic Variables, Behaviour Problems, and Adaptive Functioning Domains (Communication, Daily Living Skills, Socialization)

Predictor variables	1	2	3	4	5	6	7	8	9
1. FQOL	-	-.03	-.19	.33*	-.23	-.47**	.26	.51**	.37**
2. Child gender		-	.04	-.30*	.00	.12	-.01	-.04	.07
3. Child age			-	-.09	.12	.05	-.55**	-.35*	-.39**
4. Family income				-	-.14	-.29*	.23	.20	.20
5. Disability severity					-	.38**	-.23	-.26	-.25
6. Behaviour problems						-	-.32*	-.42**	-.47**
7. Vineland-II communication							-	.66**	.67**
8. Vineland-II daily living Skills								-	.70**
9. Vineland-II socialization									-

* $P < .01$, ** $P < .001$.

Table 7. Hierarchical Multiple Regression Analysis Predicting FQOL from Demographic Variables, Behaviour Problems, and Adaptive Skills – Summary of Model 3

Block	Predictor variable	B	SE B	β	P
Step 3					
1	Constant	3.18	.70		<.01
	Child gender	.19	.17	.10	.28
	Child age	-.03	.02	-.15	.18
	Family income	.09	.04	.24	.02
	Disability severity	-.01	.09	-.01	.91
2	Behaviour problems	-.01	.00	-.30	.01
3	Vineland-II communication	-.01	.01	-.26	.07
	Vineland-II daily living skills	.02	.01	.50	<.01
	Vineland-II socialization	-.00	.01	-.05	.72

Note. $R^2 = .17$ for step 1, $\Delta R^2 = .12$ for step 2, $\Delta R^2 = .12$ for step 3.

study to consider such characteristics in families of children with ASD in relation to FQOL. This construct takes into account many aspects of family life and with a lens that intends to capture the variability in family adaptation to raising a child with a disability. This is in contrast to examining outcomes such as parental stress and burden, which may adopt more child-centred and dysfunction-focused perspectives.

The demonstrated importance of both adaptive and behavioral characteristics is consistent with previous work examining parental distress [Tomanik et al., 2004] and family burden [Fitzgerald et al., 2002]. In Fitzgerald et al.'s [2002] study, however, communication needs were also positively correlated with family burden. In this study, communication skills were not significantly related to FQOL in either the correlation or regression analyses, which may be due to the finding that this was the least impaired domain of adaptive functioning. Communication skills are more impaired in those with comorbid intellectual impairment, and are perhaps more likely to emerge as a significant predictor in a lower functioning sample who may be nonverbal [Sparrow et al., 2005]. The present findings are inconsistent with Estes et al. [2009, 2013] who found that daily living skills did not significantly predict parenting stress or psychological distress when behavior problems were included in the model. Estes et al.'s [2009, 2013] research, however, was conducted with very young children with ASD, and research suggests that the adaptive deficits typical of this population become more marked with age [Kanne et al., 2011; Tomanik et al., 2004].

Adaptive functioning was conceptualized as being associated with more chronic support needs, and thus, we expected that its inclusion would explain additional variance above and beyond behavior problems, which may be more acute and variable in nature. Adaptive functioning did not emerge as significant when measured with a composite score (Vineland-II ABC). The authors suggest that a composite measure, in which a

Table 8. FQOL Domain Descriptives Across Daily Living Skill Level

FQOL domain	Daily living skills level		
	Low (55–70) <i>n</i> = 24 <i>M</i> (<i>SD</i>)	Moderately low (71–85) <i>n</i> = 28 <i>M</i> (<i>SD</i>)	Adequate (86–114) <i>n</i> = 32 <i>M</i> (<i>SD</i>)
Family interaction	3.45 (.93)	3.70 (.67)	4.17 (.49)
Parenting	3.24 (.65)	3.45 (.75)	4.03 (.52)
Emotional well-being	2.78 (.86)	2.95 (.90)	3.48 (.87)
Physical/Material well-being	3.83 (.72)	3.69 (.89)	4.24 (.52)
Disability-related support	3.31 (.73)	3.21 (.89)	3.87 (.62)

standard score is assigned based on the sum across relevant domains, may not be a meaningful or appropriate indicator for this population, as it fails to sufficiently capture the cross-domain functional discrepancies common in individuals with ASD. A composite measure may be appropriate, however, for other NDDs that demonstrate a relatively even pattern of adaptive deficit, as is the case for those with ID [Sparrow et al., 2005].

When the respective adaptive functioning domains were included in the model, daily living skills emerged as an important predictor of FQOL. Given that social skill deficits are the hallmark impairment of ASD, and that this was reflected in the observed adaptive profile of the sample, it is surprising that daily living skills was the only adaptive domain to emerge as significant. The latter domain assesses functioning within the areas of: personal care, including eating, dressing, hygiene, and toileting; domestic skills, such as safety awareness, and ability to provide age appropriate assistance at home, such as tidying and food preparation; and finally, as pertaining to the community context, which assesses skills such as rule following, telling time, and understanding of money. The findings indicate that it is not the most pronounced deficit of ASD (i.e., socialization) that exerts the greatest impact on FQOL, but it is instead the demonstrated difficulties with personal, domestic, and community skills that are most important. Though markedly impaired in those with ASD, socialization and communication skills likely require less tangible assistance from family members, and are, therefore, perhaps less impactful in terms of how the rest of the family functions. Moreover, socialization skills, which refer to how the individual interacts and plays with others, and copes in social situations, and receptive, expressive, and written communication skills are more often the focus of intervention, and families may feel less responsibility to ameliorate these challenges, as they are effectively addressed outside the home. Daily living skills, conversely, are not as frequently targeted within interventions for those without intellectual impairment [Farley et al., 2009]. The findings, therefore, have implications for intervention, as

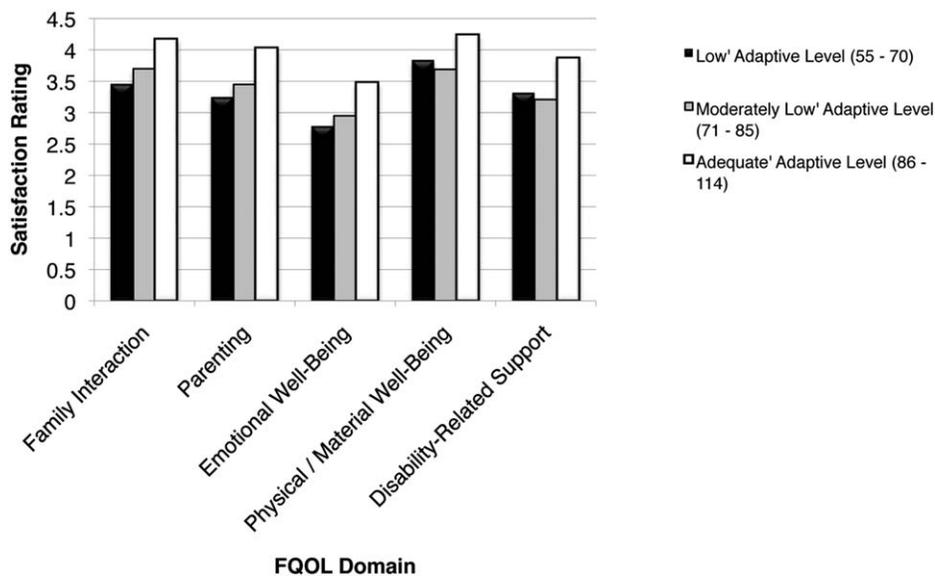


Figure 1. FQOL domain satisfaction ratings across daily living skill level.

they suggest that explicitly targeting these kinds of personal, domestic, and community skills will likely have meaningful and beneficial effects on family functioning, even for those families whose children with ASD are considered “higher functioning.”

The significant impact of daily living skill functioning level was further emphasized, as there was a significant effect of adaptive level on every FQOL domain, such that families of children whose daily living skills were in the “adequate” range had significantly higher satisfaction as compared to those whose children functioned in the “low” or “moderately low” ranges. These findings demonstrate that daily living skills have important implications across the domains of FQOL, and underscore the importance of addressing these adaptive skills.

The impact of demographic characteristics was also examined. With the exception of Cohen et al. [2014], family income has consistently emerged as an important characteristic in predicting FQOL satisfaction [Davis & Gavidia-Payne, 2009; Hu et al., 2012; Wang et al., 2004], and it emerged as significant in this research in all analyses. The findings highlight the continued relevance of family income even when child adaptive and behavioral profiles are considered. This characteristic may be particularly relevant to the ASD population, as previous research has demonstrated the greater financial impact (resulting from the child’s condition) experienced by families of children with ASD as compared to ADHD [Zablotsky, Kalb, Freedman, Vasa, & Stuart, 2014]. Furthermore, in this study, family income accounted for greater variance than previously reported in research that included families of children with varying disabilities [Hu et al., 2012; Wang et al., 2004].

In contrast, disability severity did not emerge as significant in the correlation or regression analyses, even in the first model. As previous research has found disability severity to be a significant predictor [when other functional characteristics were not included; Hu et al., 2012; Wang et al., 2004], it was expected that this variable would initially be significant, but then fail to account for unique FQOL variance once more meaningful indicators, such as behavior problems and adaptive functioning, were accounted for. “Disability severity,” however, is a very vague term, and participants likely attached widely varying meanings to the concept. This supports Wang et al.’s [2004] assertion that research should move away from broad and ill-defined constructs, such as “severity,” in favor of disability-specific characteristics. The research methods used within this study followed this suggestion, and the associated utility was demonstrated.

Limitations

There are a few limitations that are worth noting. Most individuals completed the questionnaires online, and as such, their identities cannot be independently verified. However, this weakness was outweighed by the considerable advantages this methodology afforded, as online research reaches a wider and more geographically dispersed participant base than if participants were required to come in to the lab, and also may encourage participants to respond more honestly [Holmes, 2009]. It was also considered to be a more flexible option, as it allowed caregivers to complete the surveys when it was

most convenient. This approach is, therefore, sensitive to the many demands facing the particular participant group of interest. This methodology also prevented the researchers from independently verifying caregivers' reports that their children did not have a comorbid ID. However, the DSM-V criteria for "ID" include deficits in both intellectual and adaptive functioning [APA, 2013]. As all children's Vineland-II ABC scores were within three standard deviations from the mean, they did not meet provincial criteria for "significant limitations in adaptive functioning" [CLBC, 2010]. Future research, however, should seek to replicate the findings with a sample in which IQ data is collected. This would also provide an objective measure of functioning, and would serve to corroborate caregivers' reports. The fact that the same caregiver completed all measures is also a limitation of the current study.

Another limitation relates to the participant demographics, as the majority of respondents were mothers. This is consistent with most research assessing parental and family outcomes among children with disabilities, and is also likely reflective of the distribution of parental responsibility in many families. Although previous research has demonstrated that mothers' and fathers' FQOL ratings do not significantly differ [Wang, Summers, Little, Turnbull, Poston, & Mannan, 2006], this speaks to a larger issue present in the current study as well as more broadly in the field, associated with having only one member speak on behalf of the collective family unit. Future research should make efforts to include a range of individuals from the family system, including caregivers, siblings, affected children, and individuals from extended social support networks.

All surveys were available only in English, and therefore, required participants to be reasonably proficient in this language. Although a range of ethnicities was represented in the sample, and approximately one third of participants indicated that a language other than English was spoken in the home, this study excluded families who were not comfortable enough with English to participate. This may be a particularly isolated and at-risk group of families, and the findings cannot generalize to this circumstance. It is important that future research make special effort to seek out and involve such individuals, as they may require very specific supports.

This research provides only a snapshot into FQOL at one point in families' lives. As FQOL is not stable, it is expected to fluctuate based on family experiences and transitions. Future research that adopts a family life cycle perspective, and that follows families longitudinally, will add a critical temporal layer to our understanding of the identified processes. This would provide a greater understanding of the identified characteristics. For example, although daily living skills emerged as a

critical child characteristic, adaptive functioning difficulties are known to become more pronounced with age. A long-term perspective could clarify when these functional limitations begin to negatively impact FQOL, as well as how associated challenges may differ based on support access.

Conclusion

This was the first study to examine the impact of both adaptive functioning and problem behavior in terms of QOL amongst families of children with ASD, and with an approach that acknowledged the uneven adaptive profile characteristic of this population. The demonstrated relevance of daily living skills is a critical finding, and has significant implications for intervention and future research. With regard to intervention, the findings highlight the importance of explicitly targeting children's life skills in addition to the hallmark social-communication deficits and of supporting families with practical coping strategies. We suspect that addressing these pervasive challenges will help to alleviate the considerable support demands placed on other family members and likely foster satisfaction in other areas of family life. Child adaptive functioning exerted the largest effect on the parenting FQOL domain, which focuses on guidance, discipline, and teaching [Poston, Turnbull, Park, Mannan, Marquis, & Wang, 2003]. It is expected that easing these responsibilities will exert cascading and positive effects on the other domains, perhaps resulting in more enjoyable family interaction, reduced stress, and better-fulfilled support needs.

It will be important for future research to focus on these relations with a sample that is representative of the full and heterogeneous ASD spectrum, as this will determine whether the observed findings replicate in those with comorbid ID. As this research highlighted the importance of two central aspects of the ASD functional profile, namely daily living skill functioning and behavior problems, future work should also consider the role of other disorder characteristics, such as symptom severity and comorbid conditions, as these likely also have significant implications for FQOL [Pozo et al., 2014]. It will also be important for future research to investigate the potentially ameliorative role of services and supports in the observed relation between daily living skills and FQOL. It is possible that receipt of particular services may moderate the impact of this adaptive domain and support families' satisfaction.

Acknowledgments

This article was based on data collected for the doctoral dissertation of E.G. We would like to acknowledge the many families who donated their time to participate in

this research. This research was supported by: Grant Sponsor: Social Sciences and Humanities Research Council of Canada (SSHRC); Grant Number: 767-2011-2317 to E.G.; 410-2010-0282 to G.I.; Grant Sponsor: Autism Research Training (ART) program funded by the Canadian Institutes of Health Research (CIHR); Grant Number: STN 63728 to E.G.; Grant Sponsor: Michael Smith Foundation for Health Research (MSFHR); Scholar Award to G.I.; Grant Sponsor: Laurel Foundation; Grant Number: 869431 to G.I. and E.G. The first author is currently supported by a Child and Family Research Institute/ NeuroDevNet postdoctoral fellowship.

References

- Allen, D. (2009). Positive behavioural support as a service system for people with challenging behaviour. *Psychiatry*, 8, 408–412.
- Aman, M.G., Tassé, M.J., Rojahn, J., & Hammer, D. (1996). The Nisonger CBRF: A child behavior rating form for children with developmental disabilities. *Research in Developmental Disabilities*, 17, 41–57.
- American Psychiatric Association (APA). (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.) Washington, DC: American Psychiatric Association.
- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.) Washington, DC: American Psychiatric Association.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51, 702–714.
- Berument, S.K., Rutter, M., Lord, C., Pickles, A., & Bailey, A. (1999). Autism Screening Questionnaire: Diagnostic validity. *British Journal of Psychiatry*, 175, 444–451.
- Brown, I., Brown, R.I., Baum, N.T., Isaacs, B.J., Myerscough, T., Neikrug, S., et al. (2006a). *Family Quality of Life Survey: Main caregivers of people with intellectual disabilities*. Toronto, Canada: Surrey Place Centre.
- Brown, R.I., MacAdam-Crisp, J., Wang, M., & Iarocci, G. (2006b). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 238–245.
- Centers for Disease Control and Prevention (2014). Prevalence of autism spectrum disorders among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveillance Summaries*, 63(2), (No. SS02). Retrieved on May 24, 2014, from <http://www.cdc.gov/mmwr/pdf/ss/ss6302.pdf>
- Chandler, S., Charman, T., Baird, G., Simonoff, E., Loucase, T., Meldrum, D., et al. (2007). Validation of the Social Communication Questionnaire in a population cohort of children with autism spectrum disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, 46, 1324–1332.
- Cohen, S.R., Holloway, S.D., Domínguez-Pareto, I., & Kuppermann, M. (2014). Receiving or believing in family support? Contributors to the life quality of Latino and non-Latino families of children with intellectual disability. *Journal of Intellectual Disability Research*, 58, 333–345.
- Community Living British Columbia (CLBC). (2010). Eligibility for CLBC supports and services (Policy No. SE4.023). Retrieved on May 15, 2014, from www.communitylivingbc.ca/wp-content/uploads/EligibilityPolicy-June2010.pdf
- Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability*, 34, 153–162.
- Eskow, K., Pineles, L., & Summers, J.A. (2011). Exploring the effect of autism waiver services on family outcomes. *Journal of Policy and Practice in Intellectual Disabilities*, 8, 28–35.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, 13, 375–387.
- Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., et al. (2013). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain & Development*, 35, 133–138.
- Farley, M.A., McMahon, W.M., Fombonne, E., Jenson, W.R., Miller, J., Gardner, M., et al. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, 2, 109–118.
- Fitzgerald, M., Birkbeck, G., & Matthews, P. (2002). Maternal burden in families with children with autistic spectrum disorder. *Irish Journal of Psychology*, 23(1–2), 2–17.
- Fouladi, R., McCarthy, C.J., & Moller, N.P. (2002). Paper-and-pencil or online? Evaluating mode effects on measures of emotional functioning and attachment. *Assessment*, 9, 204–215.
- Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities*, 33, 2177–2192.
- Gau, S.S., Chou, M., Chiang, H., Lee, J., Wong, C., Chou, W., et al. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6, 263–270.
- Hoffman, L., Marquis, J., Poston, D., Summers, J.A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Beach Center Family Quality of Life Scale. *Journal of Marriage and Family*, 68, 1069–1083.
- Holmes, S. (2009). Methodological and ethical considerations in designing an Internet study of quality of life: A discussion paper. *International Journal of Nursing Studies*, 46, 394–405.
- Hu, X., Wang, M., & Fei, X. (2012). Family quality of life of Chinese families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 56, 30–44.
- Iarocci, G., Virji-Babul, N., & Reebye, P. (2006). The learn at play program (LAPP): Merging family, developmental research, early intervention, and policy goals for children with Down syndrome. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 11–21.
- Isaacs, B. J., Brown, I., Brown, R. I., Baum, N., Myerscough, T., Neikrug, S., Wang, M., et al. (2007). The international

- family quality of life project: Goals and description of a survey tool. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 177–185. doi:10.1111/j.1741-1130.2007.00116.x.
- Joubert, T., & Kriek, H. J. (2009). Psychometric comparison of paper-and-pencil and online personality assessments in a selection setting. *SA Journal of Industrial Psychology*, 35(1), 78–88.
- Kanne, S.M., Gerber, A.J., Quirnbach, L.M., Sparrow, S.S., Cicchetti, D.V., & Saulnier, C.A. (2011). The role of adaptive behavior in autism spectrum disorders: Implications for functional outcome. *Journal of Autism and Developmental Disorders*, 41, 1007–1018.
- Klin, A., Saulnier, C.A., Sparrow, S.S., Cicchetti, D.V., Volkmar, F.R., & Lord, C. (2007). Social and communication abilities and disabilities in higher functioning individuals with autism spectrum disorders: The Vineland and ADOS. *Journal of Autism and Developmental Disorders*, 37, 748–759.
- Lecavalier, L. (2006). Behavioral and emotional problems in young people with pervasive developmental disorders: Relative prevalence, effects of subject characteristics, and empirical classification. *Journal of Autism and Developmental Disorders*, 36, 1101–1114.
- Lecavalier, L., Aman, M.G., Hammer, D., Stoica, W., & Mathews, G.L. (2004). Factor analysis of the Nisonger Child Behavior Rating Form in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 34, 709–721.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50, 172–183.
- Lee, L., 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.
- Lord, C., Rutter, M., DiLavore, P.C., & Risi, S. (1999). *Autism Diagnostic Observation Scale–WPS (ADOS–WPS)*. Los Angeles, CA: Western Psychological Services.
- McStay, R.L., Trembath, D., & Dissanayake, C. (in press). Stress and family quality of life in parents of children with autism spectrum disorder: Parent gender and the double ABCX model. *Journal of Autism and Developmental Disorders*, 44, 3101–3118. doi:10.1007/s10803-014-2178-7
- Naglieri, J.A., & Chambers, K.M. (2009). Psychometric issues and current scales for assessing autism spectrum disorders. In S. Goldstein, J.A. Naglieri, & S. Ozonoff (Eds.), *Assessment of autism spectrum disorders* (pp. 55–90). New York, NY: Guilford.
- Nissenbaum, M.S., Tollefson, N., & Reese, R.M. (2002). The interpretive conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities*, 17(1), 30–43. Retrieved on May 30, 2014, from <http://foa.sagepub.com/>.
- Park, J., Hoffman, L., Marquis, J., Turnbull, A.P., Poston, D., Mannan, H., et al. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research*, 47, 367–384. doi:10.1046/j.1365-2788.2003.00497.x
- Paul, R., Loomis, R., & Chawarska, K. (2014). Adaptive behaviour in toddlers under two with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44, 264–270. doi:10.1007/s10803-011-1279-9
- Perry, A., Flanagan, H.E., Dunn Geier, J., & Freeman, N.L. (2009). Brief Report: The Vineland Adaptive Behavior Scales in young children with autism spectrum disorders at different cognitive levels. *Journal of Autism and Developmental Disorders*, 39, 1066–1078. doi:10.1007/s10803-009-0704-9
- Petalas, M.A., Hastings, R.P., Nash, S., Hall, L.M., Joannidi, H., & Dowey, A. (2012). Psychological adjustment and sibling relationships in siblings of children with autism spectrum disorders: Environmental stressors and the broad autism phenotype. *Research in Autism Spectrum Disorders*, 6, 546–555. doi:10.1016/j.rasd.2011.07.015
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation*, 41, 313–328. doi:10.1352/0047-6765(2003)41<313:FQOLAQ>2.0.CO;2
- Pozo, P., Sarriá, E., & Brioso, A. (2014). Family quality of life and psychological well-being in parents of children with autism spectrum disorders: a double ABCX model. *Journal of Intellectual Disability Research*, 58, 442–458. doi:10.1111/jir.12042
- Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385–401. doi:10.1177/014662167700100306
- Rillotta, F., Kirby, N., & Shearer, J. (2010). A comparison of two family quality of life measures: An Australian study. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities: From theory to practice* (pp. 305–348). Dordrecht, the Netherlands: Springer.
- Rutter, M., Bailey, A., & Lord, C. (2003). *Social Communication Questionnaire (SCQ): Lifetime*. Los Angeles, CA: Western Psychological Services.
- Rutter, M., Le Couteur, A., & Lord, C. (2008). *ADI-R: Autism Diagnostic Interview—Revised*. Los Angeles, CA: Western Psychological Services.
- Schalock, R.L., Brown, I., Brown, R., Cummins, R.A., Felce, D., Matikka, L., et al. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40, 457–470. doi:10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2
- Sparrow, S.S., Cicchetti, D.V., & Balla, D.A. (2005). *Vineland adaptive behavior scales (2nd ed.)*. Circle Pines, MN: American Guidance Service.
- Statistics Canada. (2013). Median total income, by family type, by province and territory (All census families). Retrieved on May 24, 2014, from www.statcan.gc.ca
- Summers, J.A., Marquis, J., Mannan, H., Turnbull, A.P., Fleming, K., Poston, D.J., et al. (2007). Relationship of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programmes. *International Journal of Disability, Development and Education*, 54, 319–338. doi:10.1080/10349120701488848
- Tabachnick, B.G., & Fidell, L.S. (2013). *Using multivariate statistics (6th ed.)*. Boston, MA: Pearson.
- Tassé, M.J., Aman, M.G., Hammer, D., & Rojahn, J. (1996). The Nisonger Child Behavior Rating Form: Age and gender effects and norms. *Research in Developmental Disabilities*, 17, 59–75. doi:10.1016/0891-4222(95)00037-2

- Tomanik, S., Harris, G.E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual & Developmental Disability, 29*, 16–26. doi:10.1080/13668250410001662892
- Turnbull, A.P., Summers, J.A., Lee, S., & Kyzar, K. (2007). Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 346–356. doi:10.1002/mrdd.20174
- Vogan, V., Lake, J.K., Weiss, J.A., Robinson, S., Tint, A., & Lunskey, Y. (2014). Factors associated with caregiver burden among parents of individuals with ASD: Differences across intellectual functioning. *Family Relations, 63*, 554–567. doi:10.1111/fare.12081
- Wang, M., Summers, J.A., Little, T., Turnbull, A., Poston, D., & Mannan, H. (2006). Perspectives of fathers and mothers of children in early intervention programmes in assessing family quality of life. *Journal of Intellectual Disability Research, 50*, 977–988. doi:10.1111/j.1365-2788.2006.00932.x
- Wang, M., Turnbull, A.P., Summers, J.A., Little, T.D., Poston, D.J., Mannan, H., et al. (2004). Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years. *Research and Practice for Persons with Severe Disabilities, 29*, 82–94. doi:10.2511/rpsd.29.2.82
- Zablotsky, B., Kalb, L. G., Freedman, B., Vasa, R., & Stuart, E.A. (2014). Health care experiences and perceived financial impact among families of children with autism spectrum disorder. *Psychiatric Services, 65*(3), 395–398.
- Zuna, N., Summers, J.A., Turnbull, A.P., Hu, X., & Xu, S. (2010). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities: From theory to practice* (pp. 241–278). Dordrecht, the Netherlands: Springer.