

Examining Family Quality of Life Within the Context of a Participant-Directed ASD Funding Program in British Columbia, Canada

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Abstract

Individuals with autism spectrum disorder (ASD) will access significant supports across their lifespan, often within multiple service systems (e.g., medical, education, mental health, and social). The responsibility for service coordination most often falls to the family, and frustrations with systemic and practical barriers have significant implications for family functioning, and specifically for family quality of life (FQOL). This mixed-methods study examined caregivers' perceptions of service access within British Columbia, a province that utilizes a participant-directed model. Families described how their interactions with the service system impacted their FQOL, and differences across families representative of both the high and low ends of the FQOL satisfaction continuum were examined. Caregivers ($N = 118$) of individuals with ASD (aged 6–18 years) reported on their satisfaction with support and FQOL, and described their service navigation experiences. Fifteen caregivers also participated in follow-up interviews, in which they elaborated on their perceptions of service delivery, highlighting the associated strengths and challenges. Overall, only approximately one-quarter of participants were “satisfied” or “very satisfied” with the resources and funds available to their family, and the average satisfaction rating was low. Caregivers shared their concerns about the British Columbia service context, describing the system as inflexible, complicated, and inaccessible. Participants shared how burdensome they found funding and service coordination to be, and highlighted the strain associated with the lack of available guidance. This suggests that it is not enough to simply make families responsible for service coordination if they are not also armed with the necessary knowledge and supports. The implications for policy and practice are reviewed.

Keywords: autism spectrum disorder, British Columbia, family quality of life, participant-directed, service delivery

Introduction

Over the last few decades there have been significant improvements in the early detection and diagnosis of autism spectrum disorder (ASD), as well as increased funding to support these children. However, with the deinstitutionalization movement and accompanying trend to support individuals with disabilities in their homes and communities, much of the responsibility now rests on families (Larson, Salmi, Smith, Anderson, & Hewitt, 2013). The way in which the service system is designed in terms of funding allocation, service accessibility, and availability of guidance likely plays a critical role in how well families feel they are adapting to and supporting their child with a disability.

The current research focused on the construct of family quality of life (FQOL), and was informed by the work of Zuna and colleagues (2009, 2010) who proposed a unified theory of FQOL (see Zuna, Summers, Turnbull, Hu, & Xu, 2010 and Zuna, Turnbull, & Summers, 2009 for a visual representation). Their comprehensive model, developed based on a review of relevant empirical literature, addresses the varied and dynamic systems that interact to contribute to families' perceptions of their QOL. The unified theory incorporates various contextual levels that influence FQOL, including family-unit (characteristics, dynamics), individual family member (characteristics, demographics, beliefs), performance (services, supports, practices), and systemic concepts (the overarching systems, policies, and programs).

Within the FQOL model, disability-related services and practices are largely influenced by disability funding policies (Turnbull, Beegle, & Stowe, 2001). Thus, their potential impact on FQOL is widespread (Gardiner & Iarocci, 2012; Zuna et al., 2009, 2010). In the current study, we are guided by Zuna and colleagues' theoretical model, which suggests that overarching systemic contexts, such as funding policies, impact FQOL through families' interactions with disability service. We examined a

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particular systemic context, namely that of British Columbia, a province in Canada that has adopted a unique participant-directed service delivery model within which families are tasked with directing their child's ASD service participation. Specifically, we aim to gain insight into families' satisfaction with and perceptions of this model, thereby elucidating how aspects of participant-directed funding impact families' perceptions of their QOL.

Since 2002, families of children with an ASD diagnosis in British Columbia receive funding through the provincial Ministry of Children and Family Development (MCFD). MCFD has two autism funding programs, which currently serve approximately 11,700 children across the province (MCFD, 2015). One program serves children under 6 years, and one serves individuals between the ages of 6 and 19 years. *Autism Funding: Under 6* provides all families of children with ASD who are 5 years and under with up to \$22,000 per year toward eligible intervention services. These include applied behavior analysis (ABA) related professional services, parent and behavioral interventionist training, and intervention-related travel, equipment, and materials. *Autism Funding: Ages 6–18* (inclusive) provides families with up to \$6,000 per year toward the same kinds of eligible out-of-school intervention services. Funding for children within this age range is intended to supplement the \$18,850 per pupil funding for regular and special educational services provided to the child's school board by the provincial Ministry of Education (MCFD, 2012). This per pupil funding is not targeted to specific students (with ASD, for example), but is allocated to the particular school district to support the needs of students within their jurisdiction (BC Ministry of Education, 2016). This model is somewhat unique, as any family with a diagnosed child is eligible to access the maximum amount of funding within each program. This differs from other Canadian models, in which the amount of available funding may be tied to child characteristics (Madore & Paré, 2006; MCFD, 2012). The current study examines the perceptions of families navigating within the *Autism Funding: Ages 6–18* program, as we were interested in families' perceptions of funding and service access within the MCFD system after transitioning to a lower funding amount (i.e., \$6,000, as contrasted with the \$22,000 available through the *Autism Funding: Under 6* program).

The British Columbia model is participant-directed, meaning that families are able to allocate funds toward the services and interventions that they deem appropriate. Although families can access general navigation support through a local organization, families are not paired with support personnel with whom they have an ongoing consultative relationship, as in other participant-directed models (e.g., Warfield, Chiri, Leutz, & Timberlake, 2014). Within this model, caregivers are solely responsible for selecting all members of their child's intervention team, and act as the employer and service coordinator (i.e., they are responsible for hiring, firing, monitoring, and evaluation of performance). This model differs from other provinces and territories in that it provides families with the power to direct their child's intervention program, giving them choice and autonomy (Pugh, 2012). Funding for ASD services in Canada are provincially and territorially regulated, and models differ across each region. Some provinces offer specific program-based models through which children with ASD access ABA therapy; whereas,

in others, families receive varying supports based on their needs and regional availability (Madore & Paré, 2006).

Research on other participant-directed models in the United States provides insight into how families caring for children with developmental disabilities, including ASD, may perceive this approach. Although placing decision-making directly in the hands of families aligns with best practices of family-centered care (Beckman, 2002), research findings indicate that families have mixed feelings. Whereas some struggle with the lack of structure, perceiving the breadth of choice as burdensome and overwhelming, other families appreciate the flexibility and opportunity to customize service delivery (Freedman & Boyer, 2000; Timberlake, Leutz, Warfield, & Chiri, 2014). Warfield et al. (2014) highlight the importance of interpersonal aspects of service delivery. They found that relational coordination, defined as the extent to which families felt their relationships with service providers were open, respectful, and understanding, and characterized by shared goals, was associated with lower parenting stress and more positive perceptions about the program's impact on the family. The goal of this research was to ascertain British Columbian families' perceptions of the participant-directed *Autism Funding: Ages 6–18* program to make policy recommendations that would ultimately benefit the QOL of families navigating across various service contexts. To this end, we asked:

1. What are families' perceptions regarding British Columbia's participant-directed funding and service delivery model, and what is the perceived impact on FQOL?
2. How do the perceptions of families with high self-rated levels of FQOL differ from the perceptions of families with low self-rated levels of FQOL?

Methods

Research Design

The current study employed a mixed-methods design, as this was deemed most appropriate for addressing the significant complexity inherent within the FQOL construct. The specific approach was consistent with that of a sequential explanatory design, in which the intent was to first explore quantitative ratings of satisfaction and FQOL with a large sample, and subsequently, to utilize a qualitative follow-up component to gain a deeper and more informed understanding (Creswell, Plano Clark, Gutmann, & Hanson, 2003). With regard to the qualitative results, we anticipated participants' statements would provide a rich layer of context to numerical ratings of satisfaction and illuminate *how* service plays a significant role in families' lives (Bazeley, 2009; Creswell et al., 2003).

Participants

Survey. One hundred and eighteen family caregivers of children with ASD between the ages of 6 and 18 years participated in this study, all of whom accessed ASD funding within the MCFD *Autism Funding: Ages 6–18* program. Families represented a range

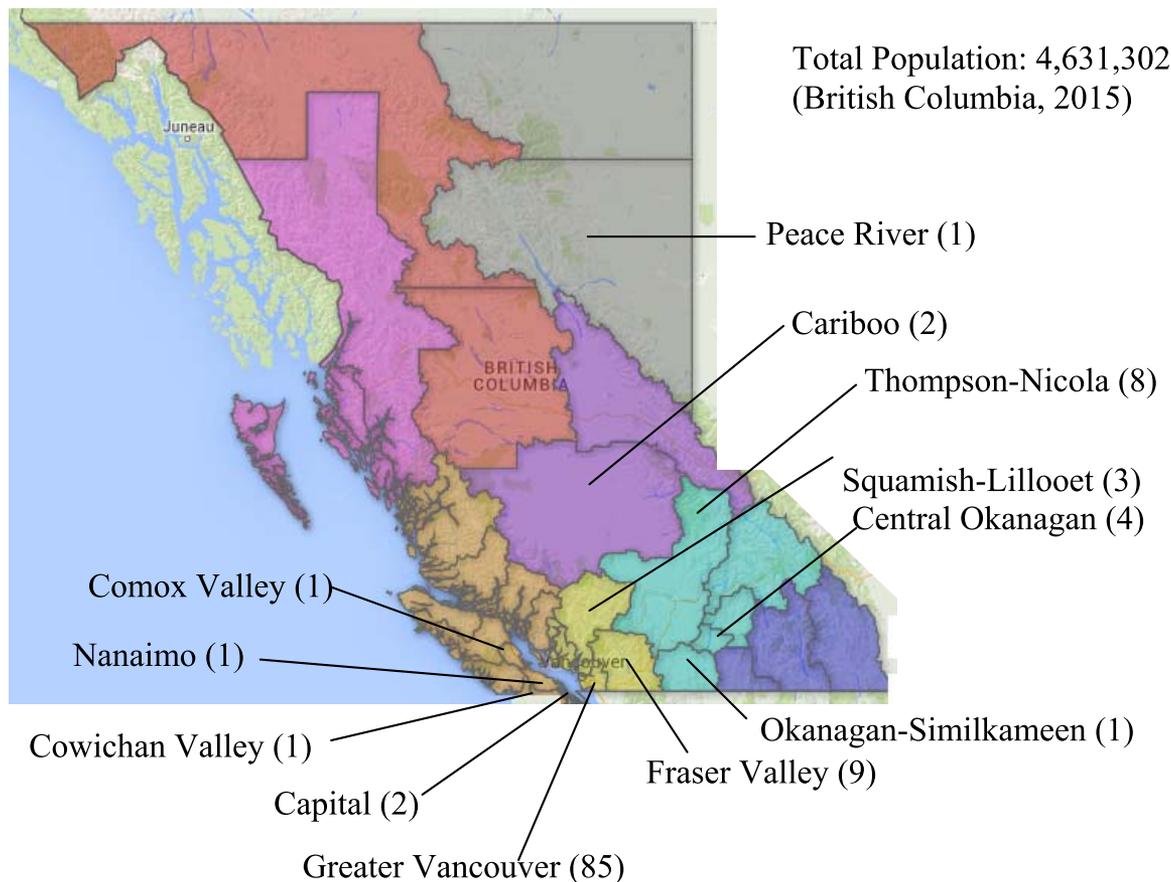


FIGURE 1

Distribution of participants by provincial Regional District (n). Image Retrieved from <http://bcstats.gov.bc.ca/StatisticsBySubject/Geography/ReferenceMaps/RDs.aspx>

of ethnicities and most (n = 106) respondents indicated that English was their family’s primary language, though 28 indicated that at least one other language was also spoken at home. Respondents ranged in age from 27 to 64 years (M = 44.5, SD = 6.84). Most (n = 85) families resided within the province’s largest regional district, with the remaining individuals coming from 11 other regional districts (see Figure 1). If participants had more than one child with ASD, they were asked to focus on the child who exerted the most impact on their family, as indicated by Rillotta, Kirby, and Shearer (2010). Participants were drawn from a larger study examining relations between various child and family characteristics and FQOL among families of children with ASD. See Table 1 for family demographic characteristics.

On average, children with ASD were 11.7 years of age (SD = 3.7). The male to female ratio was approximately 7:1. As expected, almost all (n = 114) caregivers reported that their children had at least one “other condition” aside from ASD, most frequently (n = 27) endorsing three additional conditions (range = 0–10). The most frequently reported conditions included mood/expression/anxiety problems (n = 82), behavioral

problems (n = 65), and speech or language difficulties (n = 51). See Table 2 for child demographic characteristics.

Interview. Fifteen family caregivers (representing 12 families) accessing service within the *Autism Funding: Ages 6–18* program also participated in a follow-up interview, in which they elaborated on their perceptions of service delivery. Most (n = 11) interviewees were mothers, including one who was a foster parent. See Tables 3 and 4 for interview respondent and child demographic characteristics.

Diagnostic confirmation. To receive MCFD funds, children are required to have received a standardized clinical diagnosis of ASD from a qualified pediatrician, psychologist, or psychiatrist associated with the provincial government-funded autism assessment network, or through a qualified private clinician. All children in the current study had received a diagnosis under these requirements, which include that the diagnosis be based on the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000) and confirmed using the Autism

TABLE 1
Family demographic characteristics

Demographic information	n (%)
Respondent relationship to child with ASD	
Mother	105 (89.0)
Father	12 (10.2)
Grandmother	1 (0.8)
Family ethnicity ^a	
Canadian	42 (35.6)
Asian	19 (16.1)
European	17 (14.4)
Multiple	38 (32.2)
Latin American	0
Aboriginal	1 (0.8)
African	1 (0.8)
Respondent age (years)	
20–29	1 (0.8)
30–39	31 (26.3)
40–49	63 (53.4)
50–59	21 (17.8)
60–69	2 (1.7)
Marital status	
Married or common law	90 (76.3)
Divorced or separated	19 (16.1)
Widowed	2 (1.7)
Never married	7 (5.9)
Maternal employment	
Unemployed	5 (4.2)
Employed full-time	47 (39.8)
Employed part-time	30 (25.4)
Homemaker	25 (21.2)
Student	6 (5.1)
Other	5 (4.2)
Paternal employment	
Unemployed	4 (3.4)
Employed full-time	89 (75.4)
Employed part-time	7 (5.9)
Homemaker	2 (1.7)
Other	16 (13.6)
Maternal education	
Elementary school	1 (0.8)
High school	18 (15.3)
Professional diploma	22 (18.6)
Undergraduate degree	40 (33.9)
Graduate degree	27 (22.9)
Other	10 (8.5)
Paternal education	
Elementary school	3 (2.5)
High school	27 (22.9)
Professional diploma	18 (15.3)
Undergraduate degree	33 (28.0)
Graduate degree	23 (19.5)
Other	14 (11.9)

TABLE 1
Continued

Demographic information	n (%)
Family income	
<\$20,000	7 (5.9)
\$21,000–\$49,999	23 (19.5)
\$50,000–\$79,999	21 (17.8)
\$80,000–\$109,999	29 (24.6)
\$110,000–\$139,999	18 (15.3)
\$140,000–\$169,999	7 (5.9)
>\$170,000	13 (11.0)

^aParticipating caregivers self-identified their ethnicities.

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, British Columbia has instituted standardized diagnostic practices. All

TABLE 2
Demographic characteristics of focal child with ASD

Demographic information	n (%)
Mean age (years)	
M (SD)	11.72 (3.69)
Gender	
Male	103 (87.3)
Female	14 (11.9)
Child disability severity (Caregiver report)	
Mild	44 (37.3)
Moderate	55 (46.6)
Severe	15 (12.7)
Very severe	4 (3.4)
Intellectual functioning (Caregiver report)	
Low	25 (21.2)
Low average	23 (19.5)
Average	27 (22.9)
High average	32 (27.1)
Superior	11 (9.3)
Social functioning (Caregiver report)	
Low	53 (44.9)
Low average	54 (45.8)
Average	10 (8.5)
High average	1 (0.8)
Number of other conditions	
0–3	59 (50.0)
4–7	54 (45.8)
8–10	5 (4.2)

Child disability severity, intellectual functioning, and social functioning ratings were all based on caregiver report.

TABLE 3
Family demographic characteristics—interview participants

Demographic information	Low FQOL <i>n</i>	High FQOL <i>n</i>
Respondent relationship to child with ASD		
Mother	5	6
Father	1	3
Family ethnicity ^a		
Canadian	3	3
Asian	0	1
European	2	0
Multiple	1	2
Respondent age (years)		
30–39	0	1
40–49	3	4
50–59	3	1
Marital status		
Married or common law	4	5
Divorced or separated	1	0
Never married	1	1
Maternal employment		
Unemployed	0	1
Employed full-time	4	1
Employed part-time	0	1
Homemaker	1	2
Other	1	1
Paternal employment		
Employed full-time	5	4
Employed part-time	1	0
Other	0	2
Maternal education		
Elementary school	1	0
High school	0	2
Professional diploma	0	1
Undergraduate degree	1	1
Graduate degree	2	2
Other	2	0
Paternal education		
High school	2	1
Professional diploma	1	1
Undergraduate degree	1	1
Graduate degree	0	2
Other	2	1
Family income		
<\$20,000	1	0
\$21,000–\$49,999	1	1
\$50,000–\$79,999	2	0
\$80,000–\$109,999	1	0
\$110,000–\$139,999	0	1
\$140,000–\$169,999	0	1
>\$170,000	1	3

^aParticipating caregivers self-identified their ethnicities.

TABLE 4
Demographic characteristics of focal child with ASD—interview participants

Demographic information	Low FQOL <i>n</i>	High FQOL <i>n</i>
Age (years)		
6–13	3	3
14–18	3	3
Gender		
Male	6	4
Female	0	2
Child disability severity (Caregiver report)		
Mild	3	4
Moderate	1	2
Severe	1	0
Very severe	1	0
Intellectual functioning (Caregiver report)		
Low	1	0
Low average	1	2
Average	3	3
High average	1	0
Superior	0	1
Social functioning (Caregiver report)		
Low	3	3
Low average	3	3
Number of other conditions		
0–3	3	3
4–7	3	3

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 re-diagnosed upon their arrival to British Columbia using these practices.

Measures

Satisfaction with resources and funds. In addition to asking basic questions about the respondent’s family and child with ASD (see Tables 1 and 2), the Family Demographics Questionnaire (developed by the researchers) contained an item inquiring about respondents’ satisfaction with the resources and funds available to their family (“How satisfied are you with the resources and funds available to your family?”). Responses were based on a 5-point Likert scale ranging from “very dissatisfied” (1) to “very satisfied” (5). As such, higher scores indicated greater satisfaction. Respondents were also given the opportunity to provide qualitative comments elaborating on their chosen satisfaction rating.

FQOL. The Beach Center FQOL Scale (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) assesses FQOL across five domains: family interaction, referring to the relationships among

and between family members; parenting, meaning the kinds of activities families engage in to facilitate their child's development; emotional well-being, involving perceptions of stress and support availability; physical/material well-being, referring to basic physical needs such as medical support and transportation; and disability-related support, including supports across the community contexts of school, work, and home (Park et al., 2003; Turnbull, 2004; Turnbull, Summers, Lee, & Kyzar, 2007). This tool included 25 questions with responses based on a 5-point Likert scale ranging from "very dissatisfied" (1) to "very satisfied" (5). Domain scores are 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 .74 to .87 for the subscales, and was .92 for the overall score in this study. An additional item, "Overall, how satisfied are you with your family's quality of life," from the Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities (FQOLS-2006; Brown et al., 2006) was included (representing "perceived global FQOL"), as these ratings were used to select interview participants. This procedure is described within the Interview Procedures section.

Interview. An interview guide, including topics and sample questions, was developed by the researchers based on a review of relevant literature and discussion with field experts and families. As such, an a priori theoretical orientation was adopted, in which the interview protocol was informed by the research questions (Weston et al., 2001). Within the interview, participants were asked whether they felt that FQOL was effectively addressed by service providers, and about the kinds of policies and services that would benefit their FQOL. The interview, however, was semi-structured in nature, which allowed for exploration of participant digression. An open-ended approach was utilized, as this encouraged interviewees to share their rich perceptions regarding their experiences with service delivery and the impact on FQOL.

Procedure

Survey. After obtaining approval from the University Research Ethics Board, interested participants were contacted. This convenience sample was self-selecting, and participants were recruited through a number of avenues. In particular, families were contacted through a lab database of caregivers who had participated in previous research, signed up at community events, and who had become aware of and contacted the lab through word-of-mouth. At their preference, families were contacted by email and invited to participate. Families were also invited to participate at lab-hosted events, including at a children's day camp and at four knowledge translation events (for more information, see Gardiner & Iarocci, 2017). Interested individuals were told that the "primary caregiver" should complete the survey, and that this may be a parent, sibling, spouse, life partner, or other family member. This procedure is consistent with other FQOL research (Brown et al., 2006). Families were told that the goal of the study was to gain a better understanding of FQOL, and to learn more about the domains that contribute most positively to families'

QOL, as well as those from which families derive the least satisfaction.

One hundred and thirty-four caregivers agreed to participate, of which 118 completed the survey, representing a response rate of 88%. Those who agreed to participate completed the described survey instruments online. So as not to discriminate against families without Internet access, families were also given the option to complete paper versions of the surveys, and a small proportion ($n = 9$) of participants completed paper-based versions of the tools. Multivariate analyses confirmed that survey modality did not differentially influence participant responses ($p > .05$). As per the ethics protocol, families received a small denomination gift card to a large retailer as a thank you for participating.

Interview. To address Research Question 2 (How do the perceptions of families with high self-rated levels of FQOL differ from the perceptions of families with low self-rated levels of FQOL?), it was essential that interview participants be representative of both the "high" and "low" ends of the FQOL satisfaction continuum. As such, potential participants were first selected by identifying those who rated themselves as "very dissatisfied" ($n = 6$) or "very satisfied" ($n = 9$) on the "perceived global FQOL" item ("Overall, how satisfied are you with your family's quality of life?"). These individuals were invited to participate, and seven agreed. Next, individuals who identified themselves as "dissatisfied" ($n = 24$) and "satisfied" ($n = 61$) were identified, and participants whose "overall FQOL" (i.e., mean of Beach Center FQOL Scale item ratings) ratings were most similar were invited to participate. In total, six families represented low FQOL satisfaction, and six self-rated as "high."

At participants' requests, one interview was conducted in-person, ten took place over telephone, and one occurred via videoconference. As all couple interviews took place via telephone, each participant was on a separate receiver so each individual could take part in the conversation and build on one another's statements. Although telephone interviewing may not be the preferred approach for conducting in-depth interviews, there are special circumstances, such as geographic distance and particular participant characteristics, in which the approach is considered well-suited. This participant group is an extremely strained one in terms of family demands and the often-heightened levels of stress present within their family environments (McStay, Trembath, & Dissanayake, 2014). Participants' reasons for telephone preference were consistent with this observation, and interviews were scheduled to accommodate their demanding lives, often being conducted when their children were attending therapy sessions or during the school day.

Moreover, guidelines put forth by Rubin and Rubin (2005) were followed to compensate for the lack of face-to-face contact, including having multiple contacts (range = 11–35 interactions; $M = 22$) with participants before conducting the interview. Close attention was also paid to voice changes and pauses, to determine if interviewees were sufficiently comfortable to continue. Finally, the interviewer made use of silent probes to elicit further information and to ensure that participants were given ample opportunity to reflect and complete their thoughts.

TABLE 5
Trustworthiness criteria and procedures

Criteria	Procedures
Credibility	Prolonged engagement in the field (ongoing participant correspondence; interaction at lab-hosted camps, events, and resource fairs; continued research participation) Triangulation across methods (survey and interview) and participants (representing high and low FQOL) Member checking of transcripts, themes, and written results Peer debriefing among researchers and independent co-coder Searching for discrepant evidence using constant comparative approach (Strauss & Corbin, 1998) Reporting quasi-statistics to support amount of evidence (Maxwell, 2009)
Transferability	Thick description of study context and design, participants, and themes (Creswell & Miller, 2000)
Dependability	Audit trail (raw data, coding iterations, theme development, and dated memos) Memos related to coding, project development, and theme definition Ten percent of each transcript randomly selected and independently co-coded ($k > .80$) (Krathwohl, 2009; Miles & Huberman, 1994)
Confirmability	Audit trail Peer debriefing Triangulation across sources and methods Member checking Reflexive journaling documenting research process and evolving coding scheme

Analysis

Quantitative analysis. All quantitative analyses, including the production of descriptive statistics, were conducted using SPSS Statistics, Version 23.

Qualitative analysis. Qualitative survey comments and interviews were transcribed verbatim and analyzed using NVivo10 for Windows software. For survey comments, grounded and inductive open and axial coding took place, which involved breaking comments down line-by-line to identify relevant indicators (i.e., salient words and phrases), grouping them into related concepts, and identifying overarching themes (Corbin & Strauss, 2008). A constant comparative approach was utilized, in which all the data from emergent themes were pulled together and compared (Bogdan & Biklen, 1992).

For interviews, broad-brush coding (Bazeley & Richards, 2000) first took place, in which each interview was reviewed and statements were grouped according to broad categories that corresponded with interview questions (e.g., community-based service delivery). Next, more grounded and inductive open and axial coding took place within each of these focal categories. The employed approach utilized both deductive and inductive methods, and is consistent with Weston et al.'s (2001) modified grounded theory approach, in which an a priori theoretical orientation informs the initial research and interview questions, but is also focused on exploring new and unforeseen themes that emerge as salient.

Trustworthiness. Trustworthiness, the qualitative parallel to ensuring rigour in quantitative designs, was established through adherence to Lincoln and Guba's (1985, 2013) four criteria:

credibility, transferability, dependability, and confirmability. See Table 5 for the procedures implemented to address each criterion.

Results

Survey: Satisfaction and FQOL

Descriptive statistics for our indices of satisfaction and FQOL are provided in Table 6. Overall, only 26.2% were "satisfied" or "very satisfied" with the resources and funds available to their

TABLE 6
FQOL and satisfaction descriptive statistics

Measure	M (SD)
FQOL	
Overall FQOL	3.58 (.68)
Family interaction	3.75 (.78)
Parenting	3.60 (.76)
Emotional well-being	3.03 (.95)
Physical/material well-being	3.86 (.79)
Disability-related support	3.50 (.85)
Satisfaction with available funds and resources	<i>n</i> (%)
Very satisfied	5 (4.2)
Satisfied	26 (22)
Neither	15 (12.7)
Dissatisfied	43 (36.4)
Very dissatisfied	28 (23.7)

family, and the average satisfaction rating (possible range: 1–5) was low ($M = 2.46$, $SD = 1.20$). See Table 6 for the proportion of participants who endorsed the various satisfaction levels. In terms of FQOL, the profile of domain scores, such that families reported being most satisfied with their physical/material well-being and least with emotional well-being is consistent across research with families of children with ASD (Eskow, Pineles, & Summers, 2011; Gardiner & Iarocci, 2015), as well as with other developmental disabilities (Davis & Gavidia-Payne, 2009; Summers et al., 2007).

To address our first research question (What are families' perceptions regarding British Columbia's funding and service delivery model, and what is the perceived impact on FQOL?), participants were given the opportunity to provide qualitative comments elaborating on their ratings of satisfaction with resources and funds. The qualitative comments provided by 115 caregivers were analyzed, revealing three themes. A small portion of participants ($n = 27$) shared positive feedback, whereas most ($n = 71$) indicated the provided funding amount was insufficient, and elaborated regarding the system's perceived limitations ($n = 57$).

Positive feedback. Within "positive feedback," participants shared expressions of gratitude that the program existed. They communicated an appreciation for receiving funds that could be dedicated to helping their children's development, and were grateful for the resources and expertise it afforded.

Insufficient funding. As noted, however, only a minority of participants shared positive perceptions, with most indicating that the provided amount was insufficient. Specifically, caregivers indicated that funding limitations precluded them from accessing their desired range of services and specialists, and from utilizing existing services to the extent that would be required to appropriately meet their children's needs. As a result, caregivers felt they were placed in the difficult position of having to choose among services they viewed as necessary, or were forced to supplement by accessing their savings, if able. For example, one parent said "after age 6, [there are] not nearly enough funds. We pay a minimum of \$500/month out of our savings to fund [son's] ABA." Others expressed concern about the substantial funding decreases they faced in the future. Caregivers indicated that ASD was a life-long condition, and felt that having funds cease at age 19 did not reflect this, and left individuals ill-prepared to be independent. One parent said, "It is apparent our son needs more support than is provided by the province. We know there are limits to what we can expect, but we also want our child to grow up successfully." Another said, "Much more than \$6,000 per year is needed to help our grandson achieve the help he needs to grow up to be a productive and happy person and to be able to live a semi- or fully-independent life."

Perceived service system limitations: Inflexible. Of the 57 participants who noted systemic limitations, comments most frequently ($n = 27$) reflected respondents' perceptions that the service system was inflexible due to existing restrictions on how families allocated and accessed funds. Caregivers expressed a desire for a greater range of eligible service options (e.g., family

counseling, alternative therapies, and electronic equipment), and wanted more flexibility in how they dispersed funds from year-to-year. Specifically, they suggested that they would like to be able to carry over unused funds from one year to the next, allocate more than the allotted 20% to training and equipment, and use funding for a wider range of programs, including outdoor camps and private school tuition.

Perceived service system limitations: Complicated and inaccessible. The next most frequently ($n = 26$) discussed sub-theme centered on participants' frustration with how time consuming and complicated they found service navigation to be. They indicated that qualified professionals, as well as desired programs and resources were often unavailable due to limited options in their home location or services that had prohibitively long waitlists. Services were also perceived as unavailable for particular groups, such as adolescents and young adults, and inaccessible when children did not "fit" within a program's target group. This issue arose for those who were perceived as higher functioning than other children with ASD, yet too impaired to successfully integrate within programs for typical children.

Perceived service system limitations: Burdensome for parents. Finally, participants ($n = 10$) described the system as overly burdensome for parents. The requirement that parents coordinate service delivery (i.e., choose therapeutic approach, seek and hire professionals, organize program attendance, and manage funding) was perceived as overwhelming and time-consuming, with one describing it as a "full-time unpaid job." Moreover, parents were unsure of where to find appropriate resources, and described a lack of transparency in this regard: "There's no real catalogue or discloser of services available. Mostly I have to find them myself and it's hit and miss as to how good they are." Respondents indicated that they felt very alone in this navigator role, and desired more guidance.

Interview Themes

When interviewees spoke about their experiences with service delivery, their discussions reflected three broad themes: impressions regarding autism funding, service strengths, and service gaps.

Autism funding program. Twelve caregivers shared their perceptions about the MCFD autism funding program. Although caregivers acknowledged how much they appreciated receiving the funds, all indicated that the provided amount was insufficient. They explained how the provided funding was not enough to hire a comprehensive team or to access sufficient hours with highly trained professionals. When families did not experience the benefit of having more trained (and therefore expensive) professionals to oversee and guide intervention, they worried that they may also be sacrificing implementation efficacy and ultimately child progress. Participants felt particularly frustrated when they had observed their children making gains, but were unable to continue a service or to utilize it at the intensity that they would like, thereby constraining their child's development.

Due to funding limitations, participants described the difficult position of having to choose between priorities:

The funding is not enough, it's not even close to enough, so then you're in a position where you have to choose major priorities right, 'out of all these things that my kid really needs, what does he need most desperately,' and that sucks.

Participants viewed funding as an important long-term investment. They suggested that having adequate amounts of necessary services for children with ASD would support them to achieve greater developmental gains that would be maintained over time, as well as reduce the future strain they would later exert on social systems. They acknowledged the potential of individuals with ASD to be contributing members of society, but underscored the necessity of them first receiving adequate help.

Caregivers also communicated how cumbersome they found utilizing the funding to be, as they described the responsibility of service coordination as a great burden. Parents shared how demanding it was to seek out, hire, and manage service providers, who often had high turnover. One mother described it as "running a business, whether or not you ever expected to be doing that in your lifetime, while managing your day-to-day life." Overall, they described the system as inefficient, inflexible, and inconsistent. One mother communicated how difficult it was to determine which services were classified as eligible and to understand the full scope of available options, as a particular therapy could be approved in some cases and not others. She also indicated that it was challenging to obtain clarification from MCFD, as correspondence was very slow. Others were frustrated by a perceived lack of flexibility, and wished that unused funds could be carried over from year to year, cover a broader range of therapies, and have fewer restrictions. It was clear that participants did not feel sufficiently supported to take advantage of the participant-directed model:

It's a huge problem . . . 'well we'll just hand this over to the parents and that gives them freedom of choice,' but it gives them a hell of a lot of work to do too, and if you don't do it right, the Ministry just refuses to give you the money, you know I don't want to hear the bullsh** that it's freedom of choice. True freedom of choice, these services wouldn't be costing as much in the first place and there'd be adequate funding for them.

To examine potential differences between families with high self-rated levels of FQOL as compared to those with low self-rated FQOL (Research Question 2), themes were examined across groups. When comparing families in the "high" (6) and "low FQOL" (6) groups, those in the latter spoke almost equally about all topics, as four communicated their appreciation of the funding program, but reflected on how difficult the funds were to utilize, and all indicated that it was not enough. In contrast, all "high FQOL" caregivers spoke about the insufficiency of the autism funding program, with only two indicating their appreciation, and two describing it as difficult to utilize.

Strengths. Fourteen participants shared positive experiences with services and providers, in which they felt the broader needs of the family were effectively considered in addition to the specific needs of the individual with ASD. These interviewees emphasized the positive impact of information sharing and partnering on FQOL, describing how such practices eased family life.

With regard to information sharing, caregivers highlighted both formal ASD-related community organizations and informal parent support groups. In relation to the former, these organizations were active in providing ASD-specific education and resources (e.g., books, games, DVDs), and had staff available to provide clarification regarding funding and service provision. Participants shared how much they appreciated these services, as attending education events inspired them to implement the techniques and practices about which they had learned.

In relation to the informal support groups in which participants were involved, they described them as important networking opportunities, sources of social support, and venues that facilitated the sharing of information. For example, one father described how support groups provided a useful avenue through which caregivers could learn about relevant community events and resources, which were perceived as very challenging to find (discussed in further detail below):

They all share the same frustration that they wish somebody had told them when they went through it . . . it was, 'that sucked for me' or . . . 'I would really hate for other people to go through what I went through' . . . it's so painful to discover and do some of this stuff . . . so they pay it forward by telling somebody else first.

Partnering was also identified by families as a particularly important component of service delivery. Participants appreciated programs and providers that took a holistic approach, viewing the child as embedded within their family and environment. Such programs included the individuals who played important roles in children's lives, distinguishing themselves from those that included only the child with ASD and his or her parents. For example, interviewees described summer camps that included parents, children with ASD, and their typically developing siblings. Another participant described how her child's Behavior Consultant had provided an "Autism 101" course for friends and extended family to help them understand characteristics of the disorder and to facilitate their own adjustment to receiving the diagnosis. Other service providers collaborated with professionals in other settings, as one organized team meetings and provided tailored training to the elementary school's Education Assistants. This was described as being very helpful in getting all members of the child's team, both personally and professionally, on the same page, and promoted continuity and consistency across contexts. Professionals that were particularly appreciated by families were described as "like-minded," "supportive," and "available." Participants explained how important it was that the family and professional share goals for the child. Exemplary service providers were able to effectively incorporate family priorities into treatment planning, and were receptive to adapting when necessary.

Engaging with professionals and programs that exemplified the identified characteristics was associated with a perceived

improvement in FQOL. Professionals who were able to reduce parent-identified challenging behaviors and improve communication capabilities positively impacted a family's ability to interact and function cohesively as a unit. Families appreciated service providers who worked with them to identify intervention priorities by considering behaviors that had the most impact on each member's ability to carry out daily life. One mother described how working with particular professionals had indirectly, but positively affected her family's QOL through the more direct impact on improved child behavior:

I would say yes, that has helped our quality of life because . . . one, it gives [my son] a sense of 'you know what, I can actually do this socially,' two, it's fun for him, it's actually fun. He's not actually going somewhere and trying so hard to fit in to a world he doesn't really fit in to. He can just be, and so he's more relaxed after that and easier to deal with, and so I would say yes, that has definitely had a . . . positive effect on our quality of life.

When comparing discussion content across groups, both spoke about how the right service or provider could improve FQOL (three "low" vs. four "high FQOL"). Interestingly, however, it was "high FQOL" participants who were more likely to elaborate with specific examples of positive practices, such as information sharing ($n = 7$) and partnering ($n = 7$). In contrast, only two "low FQOL" caregivers made reference to information sharing, and only one to partnering.

Gaps. All participants felt that FQOL was often not appropriately addressed as part of service delivery, and identified gaps. Most significantly, 14 participants communicated how difficult it was to find out what services were available, and subsequently to determine how well a program might fit with their family's needs and priorities. They often found out about programs through word-of-mouth; however, this did not provide them with insight into whether their own child and family would experience the same benefits. One father said,

That's what I found in the men's [support] group too, I mean everyone's like, 'how did you find out about that? How did you know about this?' Just people that peruse the Internet, but again there's a lot . . . of garbage out there . . . a lot of it is people are just hoping to get the right combination, the right information from what they're being told.

Most often, parents employed a trial-and-error approach to finding the best fit between a service and their child and family's needs. They registered their children in programs that they knew relatively little about, simply hoping for the best. Caregivers expressed great apprehension about not knowing what they were "getting into," and had significant concerns about the value of many programs. They wished for more guidance around "who is good, who is not good." These concerns appeared to be well founded, as participants recounted experiences of their involvement

in programs that were being "run like a business." In such programs, organizers did not assess the child's level of functioning or track progress, and caregivers felt taken advantage of, having wasted limited funds and valuable therapy time on something they felt had no long-term benefit. One father described the service system as:

The wild wild west, everyone for themselves . . . there is no specialist out there that you can go to who will help you, like a librarian will tell you exactly where to go . . . there's none of that, you basically have your own list of things to go see and you have to explore which works out for you.

Parents desired better awareness of available programs so they could allocate funding appropriately. One mother said, "You get thrown this money, which is great . . . but what do you do with that? You're turning left or right, you just don't know, there's nobody to walk you through it." Seven participants thought families should be paired with a service navigator upon receiving the diagnosis. This individual would explain to families what the various treatment options were, and help them to develop an individualized plan based on their child and family's unique profile of needs and strengths. One mother described it as someone to "teach [families] how to fish really, not do it for them, but teach them how . . . show them that there is a way." Four participants also identified specific service gaps, including for school-aged children and adolescents, and in rural locations where access to experienced professionals was limited. Four other interviewees spoke about their desire for greater access to services that directly served the family, such as family counselling and support for parents and siblings.

Participants communicated their perception that the MCFD funding cut-off of 19 years was arbitrary and not reflective of the delayed or inconsistent developmental trajectories of children with ASD or of their continued need for support. One mother said, "I'm struggling to see . . . what's going to change in my level of care for him that I'm no longer going to need those same supports, so I am concerned for our future quality of life." Another parent wished that there were better transition supports in place to help these individuals find employment or access adapted post-secondary education programs.

For the most part, participants within the "high" and "low" groups demonstrated the same distribution of discussion content. The only difference pertained to participants' descriptions of the service system as reactive, and one in which supports were only available once families had reached a state of crisis. This topic arose for four "low FQOL" participants, and for only one in the "high" group.

Discussion

This study examined FQOL among families caring for children and adolescents with ASD who were accessing services within the British Columbia participant-directed funding model. Participating families rated their satisfaction with available resources and funds, and FQOL, and reflected on experiences of

navigating within the provincial service context, highlighting the associated strengths and challenges.

Examination of FQOL ratings suggest that this is a group of families who face a range of struggles, both service-related and otherwise. FQOL, both overall and by domain, was notably lower than that reported in research with families of children with various developmental disabilities (Summers et al., 2007) and ASD (Eskow et al., 2011; Gardiner & Iarocci, 2015). In fact, the observed ratings were most comparable to those of families on a waitlist for a Medicaid Home and Community-Based autism waiver program, as reported by Eskow et al. (2011). Given that FQOL is conceptualized as a complex construct comprised of varied and dynamic systems (individual, family, performance, and systemic concepts) that interact with external influences to affect family life (see Zuna et al., 2009, 2010), there are a multitude of factors that influence it, and we cannot suggest that these lower ratings are due only to the unique funding context within which participating families were navigating. However, families' ratings of satisfaction with available funds and resources revealed that service was indeed a prominent concern, and future research should seek to isolate relevant service variables to investigate the relation to FQOL within the participant-directed environment.

The qualitative findings provided important context to these satisfaction ratings, as families were given the opportunity to share their rich perceptions and experiences. There was great consistency across the themes identified in the full sample as compared to those that emerged within follow-up interviews. Although families appreciated that funding was available, caregivers' discussions of service delivery painted a very discouraging picture of what it is like to access supports within a system they described as opaque. One of the most significant concerns was the prevailing lack of guidance to help families navigate through complicated funding access systems and to choose among the many available intervention programs and approaches, as well as the perceived lack of follow-up. In particular, participants' perceptions of a lack of transparency emerged as the predominant theme. Within this context, caregivers communicated how difficult it was to determine what was available to them, how a particular service or resource might fit with families' needs and priorities, and to get a sense of its quality. They also felt they had to be vigilant to ensure that professionals did not take advantage of them. Overall, they perceived a significant mismatch between a service system that promulgated an emphasis on family choice and autonomy (by allowing families to direct funding allocation) and their experiences actually navigating the system. Participants shared how burdensome they found funding and service coordination to be, and how they felt that without sufficient guidance, they were operating in the dark, employing a trial-and-error approach, and "just hoping to get the right combination." These experiences combined with the perceived funding insufficiency, left families feeling strained, both emotionally and financially, and concerned that their children's developmental progress was being hampered.

Families identified partnering and information sharing as important and desirable approaches, consistent with previous research (Davis & Gavidia-Payne, 2009; Summers et al., 2007; Warfield et al., 2014). New information was revealed when we compared families with high self-rated levels of FQOL to those who self-rated as low on interview themes. Specifically, "high

FQOL" caregivers were more likely to recount positive experiences with service providers, and shared how working with professionals who addressed family needs, in addition to those of the child, in individualized and flexible ways exerted positive effects across the domains of family life. This suggests that the identified practices are meaningful to families, as they facilitate their positive and active engagement with the service system and promote their QOL.

The significant stress families experience in navigating the service system is not a new theme. Similar findings are present within FQOL research that is more than a decade old (e.g., Poston et al., 2003), thereby suggesting that practice is significantly lagging behind theory in this regard. This research also corroborates previous work indicating that it is not enough to simply make families responsible for service coordination if they are not also armed with the necessary knowledge and supports. Without such guidance, family-directed service is not viewed as empowering, as is suggested within the family-centered philosophy, but is instead perceived as overwhelming, burdensome, and time consuming (Freedman & Boyer, 2000; Valentine, 2010).

Limitations

The conclusions must be considered within the context of the limitations of the current study, primary of which is the fact that 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. The researchers attempted to mitigate this concern in the qualitative component by inviting "caregiving partners" to participate. However, only three agreed, and all were from "high FQOL" families. This is consistent with the dispersion of themes across satisfaction levels that emerged within other components of the interview (not described here), in which "low FQOL" caregivers spoke more about marital discord and the lack of spousal cohesion with regard to parenting approach. The utilized research methodology provides invaluable insight into the challenging nature of day-to-day life for families of children with ASD, and participants often speculated about other members' perspectives, including siblings, spouses, and children with ASD. The fact that much of the data is representative of only one family member's perspective, however, is a limitation. Future work that attempts to incorporate Poston et al.'s (2003) astute definition of "family" into research designs, making efforts to include "the people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis" (p. 319) will greatly advance the field's understanding of the complex and interactive nature of FQOL processes. Gauging the perspectives of individuals with ASD whenever possible will also go a long way in helping to provide insight into their QOL, and specifically into the supports that they see as necessary. Similarly, seeking the perspectives of siblings is critical as they are often the ones to carry the responsibility for supporting the individual with ASD once primary caregivers are no longer able (Orsmond & Seltzer, 2007).

Conclusions and Implications for Policy

Programs supporting families caring for individuals with ASD vary greatly in their design, resource allocation, and effects on families. Although diversity in approach may be useful in promoting local innovations and necessary given the unique context in each region, there remains uncertainty with regard to what constitutes best practice and policy. The heterogeneity in ASD poses many challenges, not the least of which is the variation in family support needs. Although it may be difficult to develop an evidence base to identify best practices for supporting all families, a few clues emerged from our study of the British Columbia participant-directed ASD funding model.

First, the findings suggest that funding services for children with ASD is necessary, though not sufficient to address the individualized and varied needs of affected families. Many families identified the need for a service navigator who could help them to learn about available intervention options, but importantly to determine how one might fit with their individual needs and strengths. This element is present within other participant-directed models (e.g., Timberlake et al., 2014; Warfield et al., 2014), and is also consistent with Eskow, Chasson, and Summers' (2014) work, in which more intensive individual support services were associated with perceived FQOL improvement over the previous year.

Second, the perceived inflexibility of the overall service system was another significant issue. Families expressed that they were unable to successfully exercise true choice and autonomy with regard to service provision as they perceived this responsibility as burdensome and their capacity as restricted. Giving families greater flexibility in how they allocate funds (e.g., for a greater range of therapies and services, and allowing carry-over from year-to-year) was suggested as a way to foster their sense of empowerment, thus facilitating a view of service coordination as an opportunity rather than an encumbrance. However, this presupposes that appropriately trained professionals and evidence-based therapies are available to be accessed. A recently released national report by the Canadian Autism Spectrum Disorders Alliance (2014) indicates that "lack of resources and services" was the most frequently cited barrier to service identified by a large sample of caregivers ($n = 508$) of preschoolers (73%), school-aged children (72%), and adults (61%) with ASD, as well as by 89% of participating professionals ($n = 301$) in British Columbia, highlighting the pervasive nature of this issue. Many caregivers in the current study similarly described programs and resources as difficult to find and access, both within the qualitative survey comments and interviews. Caregivers first require access to a sufficiently diverse range of interventions, programs, and therapies to execute flexibility and choice in how they engage with child and family services.

Finally, few families shared examples of practices that were based on family-centered principles, such as partnering, individualization, and considering the interconnectedness of the family unit, suggesting there is a disconnect between such principles and their application (Dodd, Saggars, & Wildy, 2009; Dunst, 2002; McWilliam, Snyder, Harbin, Porter, & Munn, 2000; Trivette & Dunst, 2005). The few families that did provide examples of open relationships with their service providers identified

themselves as truly partnering in service delivery, and communicated greater satisfaction with their FQOL. Professionals are encouraged to view "the family" with a holistic and systems-informed lens, within which the child and family's needs are not viewed as distinct, but inextricable. Participants noted that easing child-specific demands exerted positive effects on the family's interactions; however, it is also important that all family members' circumstances are considered and addressed. When families are given the opportunity to identify their strengths, needs, and priorities, they are empowered to participate as partners in service delivery.

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