

FAMILY QUALITY OF LIFE IN A CANADIAN SAMPLE

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Abstract

Background Past studies have evaluated the psychometric properties of the Family Quality of Life Survey – 2006 (FQOLS-2006). Analyses are sometimes conducted on data from different countries, combined. A country's healthcare and social services are likely to impact FQOL among families with members with developmental disabilities, and these can vary widely between countries. The current project contains three studies, each evaluating different aspects of the FQOLS-2006 with a uniquely Canadian sample.

Methods Study 1 employs Confirmatory Factor Analysis to evaluate the factor structure of the FQOLS-2006 to determine whether its nine domains are reliably measured by its six dimensions, and whether Overall FQOL is reliably measured by its nine domains. Study 2 investigates the relationship between general information questions in the A Sections, and domain-level FQOL in the B Sections, in the Health, Finances and Support from Services domains, using chi-square and qualitative analyses. Study 3 compares domain-level FQOL ratings of one- vs two-parent families, and of families with one vs more than one member with DD.

Results In study 1, with some additional modifications in five domains, all nine domain models fit the data well. The freely estimated Overall FQOL model fit the data very closely. Study 2 found strong relationships between Sections A and B; respondents reporting challenges in Section A reported low FQOL at a higher rate in Section B. An additional finding was that, while health and services FQOL were generally high, financial FQOL was lower in our sample. In study 3, one-parent families reported significantly lower FQOL than two-parent families only in the Finance domain. Small sample size rendered the results of the comparison of families with one vs more than one member with DD uninterpretable.

Conclusions Study 1 suggests the factor structure of the FQOLS-2006 is valid for use with urban Ontarian families. Study 2 suggests good convergent validity between Sections A and B. Studies 2 and 3 suggest that finances may be a particular source of stress for the families in our sample. Limitations, future research and clinical implications are explored in the discussion section.

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Table of Contents

Abstract	ii
Acknowledgments	iii
Table of Contents	iv
List of Tables	v
List of Figures	vi
List of Appendices	vii
 Introduction	 1
Methods	17
Data Analysis and Results	
Study 1.....	20
Study 2.....	31
Study 3.....	54
Discussion	60
References	82
Appendices	96

List of Tables

Table 1 <i>Characteristics of participants</i>	<i>p. 18</i>
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Study 1

Table 2 <i>Domain models with Attainment and Satisfaction error terms covaried</i>	<i>p. 24</i>
Table 3 <i>Domain models with Attainment and Satisfaction and domain-specific error covariances</i>	<i>p. 26</i>
Table 4 <i>Completely Standardized Factor Loading Estimates for Model 2</i>	<i>p. 27</i>
Table 5 <i>Overall FQOL model, freely estimated</i>	<i>p. 31</i>
Table 6 <i>Completely Standardized Factor Loading Estimates for Overall FQOL Model</i>	<i>p. 31</i>

Study 2

Table 7 <i>Health FQOL by health of person with DD, collapsed</i>	<i>p. 36</i>
Table 8 <i>Health FQOL by health of other family members, collapsed</i>	<i>p. 38</i>
Table 9 <i>Health FQOL by health of person with DD and health of other family members, combined, collapsed</i>	<i>p. 40</i>
Table 10 <i>Finance FQOL by perceived income, collapsed</i>	<i>p. 45</i>
Table 11 <i>Finance FQOL by basic needs met, collapsed</i>	<i>p. 49</i>
Table 12 <i>Services FQOL by services needed/not getting, collapsed</i>	<i>p. 52</i>

Study 3

Table 13 <i>Descriptive Statistics and Independent Samples tests of Domain-Level FQOL by Parent Group</i>	<i>p. 57</i>
Table 14 <i>Descriptive Statistics and TOST procedure for Domain-Level FQOL by Family Group</i>	<i>p. 58</i>
Table 15 <i>Correlation Matrix of FQOLS-2006 Subscales</i>	<i>p. 60</i>

List of Figures

Study 1

Figure 1 *Factor structure for Health of the Family domain* p. 23

Figure 2 *Factor structure of overall FQOL* p. 30

Study 2

Figure 3 *Crosstabulation of Health FQOL with health of person with DD* p. 35

Figure 4 *Crosstabulation of Health FQOL with health of other family members* p. 37

Figure 5 *Crosstabulation of Health FQOL with health of person with DD and health of other family members, combined* p. 39

Figure 6 *Crosstabulation of Finance FQOL with perceived income* p. 44

Figure 7 *Crosstabulation of Finance FQOL with basic needs met* p. 48

Figure 8 *Crosstabulation of Services FQOL with services needed/not getting* p. 51

List of Appendices

Appendix A	<i>FQOLS-2006</i>	<i>p. 96</i>
Appendix B	<i>High Health FQOL and Health Concerns – Both</i>	<i>p. 140</i>
Appendix C	<i>High Health FQOL and Health Concerns – Members with DD</i>	<i>p. 141</i>
Appendix D	<i>High Health FQOL and Health Concerns – Other Family Members</i>	<i>p. 142</i>
Appendix E	<i>High Finance FQOL and Below Average Perceived Income</i>	<i>p. 143</i>
Appendix F	<i>High Finance FQOL and Not All Basic Needs Met</i>	<i>p. 145</i>
Appendix G	<i>High Services FQOL and Services Needed/Not Getting</i>	<i>p. 146</i>

Introduction

Historically, families with a member with a severe disability would provide care for the person in the family home. From the mid 1800s to the mid 1900s, institutionalization of people with severe disabilities came to be considered best practice (Cummins, 2001). With the emergence of the concept of “normalization” in the 1970s, advocating that people with disabilities should live in conditions that conform to the standards of the general population, a movement toward deinstitutionalization began, and caregiving responsibility shifted back to the family (Cummins, 2001; Samuel, Rillotta et al., 2012). Although this shift was propelled by an anticipated increase in quality of life for the individual with the disability and a reduction in taxpayer expenditures, it occurred without consideration of ability and willingness of families to act as main caregivers (Samuel, Rillotta et al., 2012) or the impact it would have on families (Cummins, 2001). Having a family member with a disability is often difficult for each family member and can have a negative impact on a family’s quality of life (Samuel, Rillotta et al., 2012; Summers et al., 2005). Thus, on the heels of quality of life (QOL) research that began in the early 1990s, largely focusing on the individual (Samuel, Rillotta et al., 2012), emerged a literature about family quality of life (FQOL) among families with one or more member with an intellectual disability.

Terminology in the field of intellectual and developmental disability is constantly evolving, and nomenclature varies from country to country. For the purpose of the current paper, the term ‘Developmental Disability’ (DD) will be used throughout, understood to encompass Intellectual Disability (ID) and Autism Spectrum Disorders (ASD), and these could also include co-occurring physical disabilities.

Interest in QOL research in the DD literature emerged in part from a shift away from viewing scientific, technological, and medical advances as the only way to improve QOL among this population. Researchers began to consider complex interactions of family, community, and environmental factors improving quality of life for the individual with DD (Verdugo et al., 2005). There is agreement in the literature about some key elements of QOL; it is viewed as a social construct, consisting of a combination of factors that are shared among people, as well as factors that are idiosyncratic to individuals (Brown & Brown, 2003; Samuel, Rillotta et al., 2012; Verdugo et al., 2005). There is also agreement about some of the life domains associated with QOL, such as physical, emotional, and material well-being, community living and social belonging (e.g., Brown & Brown, 2003; Schalock, 2004). Based on this literature, researchers over the past 25 years have developed and validated several measures to evaluate QOL, many for individuals with DD (Isaacs et al., 2007). Verdugo and colleagues (2005) described five characteristics that underpin the accepted approach to measuring QOL:

- 1) it is multidimensional involving core domains and indicators;
- 2) the use of methodological pluralism requiring subjective and objective measures;
- 3) the use of multivariate research designs to evaluate the ways personal characteristics and environmental variables relate to the person's assessed QOL;
- 4) the incorporation of a systems perspective that captures the multiple environments impacting people at the micro, meso, and macro levels; and
- 5) increasing involvement of persons with disabilities in the design and implementation of QOL oriented assessment, research and evaluation. (Verdugo et al., 2005, p. 707)

QOL is a complex issue among people with intellectual and developmental disabilities and their caregivers. It requires evaluation of the disability itself and the support required by the person with the disability (Samuel, Rillotta et al., 2012). A basic assumption of QOL is the idea that an individual should have control over his or her own life (Brown & Brown, 2005; Brown & Brown, 2009), but this idea depends on an individual with DD being able to communicate his or

her preferences (Brown & Brown, 2009). Misunderstandings may lead to individuals feeling denied their right to make decisions about their own lives for themselves. Also, dilemmas sometimes arise when the desires of an individual with DD are viewed by caregivers or service providers not to be in the individual's best interest (Brown & Brown, 2003). In terms of evaluating QOL, comparisons between self-reports and caregiver-reports of QOL in individuals with DD have been demonstrated not to be interchangeable. Though there appears to be sizeable agreement, researchers have concluded that different perspectives should be included in QOL measurement (Simões & Santos, 2016; Turnbull et al., 2007).

In the early 2000s, investigation into *family* quality of life in the field of intellectual and developmental disability was motivated by family members' calls for it. Caregivers welcomed the research on individual QOL but expressed a need for consideration of FQOL as well (Samuel, Rillotta et al., 2012). Thus, FQOL research and measures began to emerge (Brown et al., 2000; Brown, Brown et al., 2006; Samuel, Rillotta et al., 2012). The basic notion on which FQOL is predicated is that everyone deserves quality of life, including people with disabilities as well as their caregivers (Samuel, Rillotta et al., 2012; van Heumen & Schippers, 2016). The QOL factors Verdugo et al. (2005) outlined (above) are also relevant to FQOL, which has been conceptualized as a multidimensional social construct (Samuel, Rillotta et al., 2012; Zuna et al., 2011). In creating their FQOL-2000 measure, the International Quality of Life Project (Isaacs et al., 2007) integrated some of the conceptual framework of QOL into their measure. The basic tenets of QOL incorporated into the concept of FQOL are that QOL is:

- (1) multidimensional and influenced by many factors;
- (2) comprised of generally the same dimensions for all individuals or groups, but that some aspects may hold more importance or salience than others for some individuals or groups;
- (3) inclusive of both subjective and objective elements;

- (4) best studied using multiple methodologies (qualitative and quantitative); and
- (5) studied for the specific purpose of understanding and improving life for individuals with ID and their families. (p. 179)

Thus, when creating the measure, FQOL was conceptualized using multiple concepts across nine domains of family life (e.g., health, finances), each measured across five dimensions (e.g., opportunities, initiative) (Brown et al., 2000). With only small changes to some wording, these same domains and dimensions were carried over into the FQOLS-2006 (see Appendix A), and a sixth dimension, *Importance*, was added (Brown, Brown et al., 2006). The first part of the FQOLS-2006 is called *About Your Family*, and asks questions designed to clarify respondents' family composition. The following nine parts assess the construct of FQOL according to nine domains of family life (Health of the Family, Financial Well-Being, Family Relationships, Support from Other People, Support from Disability Related Services, Influence of Values, Careers and Preparing for Careers, Leisure and Recreation, Community Interaction). Each of these nine parts of the survey contains two sections. Section A gathers general information about the domain in question. In Section B, the domain is measured across six dimensions (Importance, Opportunities, Initiative, Attainment, Stability, Satisfaction), one question per dimension, each measured on 5-point Likert-type scales. Respondents are asked the same six dimension questions for each domain. The final part of the survey is called *Overall Family Quality of Life* and asks respondents for their general impressions regarding their family's quality of life. This part consists of open-ended questions, as well as two items evaluating overall FQOL (attainment and satisfaction) on 5-point Likert-type scales.

Psychometric Properties

The FQOLS-2006 has been, and currently is being used in FQOL projects in several countries across the world. Studies have been conducted to evaluate this measurement tool's psychometric properties. In 2009, a team of researchers provided a descriptive analysis of the dimensions and domains of the FQOLS-2006 to explore the relationships between them, and to overall FQOL, using a small Canadian sample (N=35) (Werner et al., 2009). With regards to the dimensions, Importance was rated highest, and Stability was rated lowest, when averaged across domains. Correlation analyses showed that Attainment and Satisfaction were associated in six of the nine domains, most strongly in the domains of Financial Well-Being and Family Relationships. However, the researchers concluded that since the association between Attainment and Satisfaction was not found in all domains, it was important to retain both dimensions when measuring FQOL. With regards to the domains, Health of the Family was given the highest Importance rating on average, significantly higher than many of the other domains. Opportunities ratings were higher in the Health domain than in the Financial, Services, and Community domains, and higher in the Family domain than in the Financial domain. Initiative and Attainment ratings were higher in the Family domain than in the Financial domain. Finally, global satisfaction (i.e., responses to the question, "Overall, how satisfied are you with your family's quality of life?") was found to be correlated with composite satisfaction scores from some of the nine domains but not others, the highest associations being with composite FQOL in the Health and Family domains. The researchers concluded that the gap between Importance, which was rated highly across domains, and Attainment and Satisfaction, which were rated lower, was indicative of a need for increased supports. Health, however, was rated highly on Importance, Opportunities and Attainment in their study. Finally, the researchers explained that moderate Satisfaction scores were found across all domains.

Issacs and his colleagues (2012) sought to study the measure's construct validity, using confirmatory factor analysis (CFA) to test the factor structure of the FQOLS-2006, with data from four countries: Australia, Canada, Nigeria and the USA. They opted to analyze the data from Nigeria separately, and to analyze the data from Australia, Canada and the USA together – the “three countries” data set. They explained that their reason for doing so was that Australia, Canada and the USA are similar in terms of language, culture and economic development, where Nigeria is an emerging economy, and culturally and linguistically different from the other three countries (Isaacs et al., 2012). They analyzed the data in two phases. In the first phase, they sought to test the hypothesis that each of the nine domains is reliably measured by six dimensions that combine to form a unidimensional scale. In the second phase, they tested the hypothesis that FQOL is a unique construct that is reliably measured by the survey's nine domains. In Phase 1, in both the Nigerian and three countries data sets, consistent with the findings of Werner's study (Werner et al., 2009), the researchers found that respondents gave high Importance ratings across all nine domains. This resulted in serious skewness. As a result, they opted instead to examine one-factor, five-indicator CFA models for each domain, excluding the Importance dimension. They also found the Stability dimension to be problematic (e.g., low factor loadings on certain domains), for both data sets. Thus, they ran the analyses again, excluding both the dimensions of Importance and Stability, using only the four remaining dimensions as indicators. Doing so resulted in good model fit for all nine domains, in both data sets, with additional error covariances added to some models. In Phase 2, they tested the overall FQOL model using the nine domain means, computed based on the four dimension ratings (excluding Importance and Stability). The three countries data fit the freely estimated model very closely. The Nigerian data fit the model well when the researchers specified error

covariances between some domains. Overall their second hypothesis was supported; the FQOL construct was found to be represented by the nine domains of the FQOLS-2006 in both data sets.

More recently, Perry and Isaacs (2015) examined the convergent validity of the FQOLS-2006 by comparing it to the Beach Center FQOL Scale, a validated measure of FQOL. They administered, scored, and compared responses to both measures from 62 Canadian families with school-aged children with ID, ASD, or both. They hypothesized a strong correlation between the total scores of the two measures. They also predicted a strong correlation between subscales with similar content (Health of the Family with Emotional Well-being, Financial Well-being with Physical Material Well-being, Family Relationships with Family Interaction, Family Relationships and Parenting, Support from Disability-related Services with Disability-related Supports) and not between subscales with dissimilar content. For the FQOLS-2006, the sums of Attainment and Satisfaction scores were used as domain and total scores, as they are considered outcome indicators of FQOL (Isaacs et al., 2007; 2012). The total scores of the two measures, as well as subscales expected to correlate, were strongly correlated. There was also an expected lack of correlation between subscales with dissimilar content. There were, however, several unexpected correlations between subscales (e.g., between the FQOLS Health domain and the Beach Center Family and Caregiving domain). The researchers concluded that the FQOLS-2006 exhibits good convergent validity with the Beach Center Scale overall, but that more research is needed to explain the unexpected correlations.

A team of researchers in the USA undertook to evaluate the psychometric properties of the FQOLS-2006 using a similar methodology (Samuel et al., 2016). Their sample consisted of 65 participants, of whom the majority belonged to a racial or ethnic minority group and approximately half reported an annual household income of \$27,000 or less. The researchers

evaluated the internal consistency of the FQOLS-2006, and evaluated its concurrent validity by comparing it to the Beach Centre FQOL Scale. For the FQOLS-2006, the sum of Attainment and Satisfaction scores were used as domain and total scores. With regards to internal consistency, the researchers found that the two-item global FQOL scale (i.e., responses to the questions “Overall, how would you describe your family’s quality of life?” and “Overall, how satisfied are you with your family’s quality of life?”) was similar to that of the 18-item total FQOL scale (the sum of Attainment and Satisfaction scores for each domain). Domain-level internal consistency, however, ranged from weak to good, with Health, Support from Services and Finances being the least reliable. With regards to concurrent validity, the researchers predicted several domain-level correlations between subscales of the FQOLS and Beach Centre FQOL Scale: Health with Physical Material Well-being, Finances with Physical Material Well-being, Careers with Physical Material Well-being, Family with Family Interaction, Family with Parenting, Support from Others with Emotional Well-being, Support from Services with Disability-related Support, Influence of Values with Emotional Well-being, Leisure and Recreation with Community, and Community Interaction with Community. They concluded that their results provided empirical support for the validity of only five of the nine FQOLS domains (Family Relationships, Support from Others, Support from Services, Leisure and Recreation, Community Interaction). They noted that their finding that the domain of Financial Well-being was not significantly associated to any of the Beach Centre FQOL Scale domains runs counter to the findings of Perry and Isaacs (2015). They explained that the fact that Perry and Isaacs’ sample of families was from higher socio-economic backgrounds likely accounts for the FQOLS-2006’s Finances and Careers domains being associated with the Beach Centre FQOL Scale’s Physical Material Well-being and total FQOL score.

In 2018, Samuel and her colleagues (Samuel et al., 2018) conducted a study to evaluate the internal consistency, construct and criterion validity of the FQOLS-2006 for use with socio-economically disadvantaged families. With regards to internal consistency, seven of the nine domain subscales showed excellent internal consistency, while that of Health and Finances was moderate. Internal consistency of the global FQOL scale (consisting of two items relating to overall FQOL rating and satisfaction) was excellent, and of the total FQOL scale (consisting of 54 items relating to each of the six dimension questions for each of the nine domains), even stronger. With regards to construct validity, the researchers concluded that each domain constituted a latent factor that can be measured using six indicator variables relating to the measure's six dimensions. However, many factor loadings were low in the domains of Health and Finances, suggesting that the structural validity of these domains is weak within their sample. The Support from Other People and Leisure domains were also problematic. In summary, the researchers concluded that the factor structure of the remaining five domains was demonstrated to be valid with their sample. Consistent with the findings of Isaacs et al. (2012), Stability and Importance were found to have low factor loadings across domains. However, the researchers opted to retain these dimensions when computing the domain subscales for the total FQOL model, citing their clinical importance as justification. Their data fit the hypothesis that FQOL is a latent factor that can be measured using nine indicator variables relating to the nine domain scores measured by the six dimensions, only when the error terms for the Support from Others and Support from Services were allowed to covary. The researchers concluded that their results provided a moderate level of evidence to support calculating a total FQOL score based on the nine domain scores, and highlighted redundancy between informal and formal supports. Finally, to assess criterion validity, the researchers compared scores on the FQOLS-2006 with

scores on the short version of the measure. They found that the total score and all subscale scores were significantly correlated, though there was only a moderate level of convergence between the two versions.

Following their 2012 study described above, Isaacs and colleagues (Isaacs et al., 2011) tested a path model of the dimensions measured in the FQOLS-2006 using a Canadian sample of 100 respondents. Here, Attainment and Satisfaction were treated as outcome variables while the remaining four dimensions were treated as predictor variables. The researchers found that the dimension of Opportunities had the highest total effect on the dimensions of Attainment and Satisfaction, which suggests that providing opportunities that are important to families is the most effective way to increase FQOL. They found that Initiative positively predicted Opportunities, suggesting that trying harder allows families to find more options to improve FQOL. The researchers found a direct negative effect of Importance on Satisfaction and concluded that more research was needed to explain this relationship. Contrary to the results of the 2012 study, the researchers found that Importance and Stability did have an effect on overall domain-level FQOL (the sum of Attainment and Satisfaction), albeit an indirect effect. That is, they found a significant pathway from Stability to Opportunities, suggesting that a family's situation may improve or decline depending on the opportunities they have in a given domain, and as noted above, Opportunities was found to have a direct effect on Attainment and Satisfaction. They also found a significant pathway from Importance to Initiative which was found to have a direct effect on Attainment. Furthermore, there was a trend toward a negative pathway from Initiative to Satisfaction (it was significant in earlier iterations of the model but not in the final, best-fitting iteration), suggesting that individuals may be less satisfied when they feel they must work very hard to improve FQOL.

Canadian Data

Potential confounds arise when combining data from different countries with different healthcare systems. In their 2012 study using data from four countries, Isaacs and his colleagues noted that, while Australia, Canada and the USA are considered to be developed, ‘Western’ societies with similar values, they have very different healthcare systems (Isaacs et al., 2012). Indeed, when they examined internal consistency, the Health domain was the least reliable, and they suggested this may be due to the countries’ different healthcare systems. The USA has privatized healthcare, and the public systems in Australia and Canada are very different from one another (Papanicolas et al., 2018; Squires, 2015; The Commonwealth Fund, 2016). In their study, Isaacs’ team aimed to examine the universality of the FQOL construct (its *etic* properties) across countries (Isaacs et al., 2012). The cultural differences of the participants, however, were not captured, thereby reducing the generalizability of the results to each country.

There is a need for additional research to determine the usefulness of the FQOLS-2006 in Canada. The construct of QOL has been found to have both *etic* (universal) and *emic* (culture-bound) properties (Schalock et al., 2005), suggesting that country-specific research adds value to understanding the construct as it operates in a given culture. We now have a large database with which to study the FQOLS-2006 with a uniquely Canadian sample. Thus, our first area of investigation was to examine whether the factor structure of the FQOLS-2006 is valid for use with Canadian families, more specifically, urban families in Ontario.

Much of the literature on FQOL has been based on US data. There are major differences between healthcare in the USA and Canada (Béland & Waddan, 2017; Squires, 2015; Thomas & Biette, 2014). Privatized vs public healthcare has major implications with regards to services for

families with a member who has a disability. It can mean the difference between medical and social services being out-of-pocket or covered by a healthcare plan. Béland and Waddan (2017) suggest:

Perhaps the most obvious institutional difference between these two neighbors is seen in respect to their health care systems. The Canadian Medicare system guarantees government-funded health care for all Canadians. In contrast, the United States has allowed a situation to continue where many millions of its citizens and residents live with the knowledge that ill health could also lead to economic insecurity. (p. 82-83)

Three domains of the FQOLS-2006 that are likely to be impacted by the healthcare system and social services in a given country are Health of the Family, Financial Well-Being and Support from Disability Services. Canadian healthcare is universal and is delivered through provincial and territorial systems of publicly funded health care. In Ontario, the Ontario Health Insurance Plan (OHIP) covers a wide range of basic health and emergency services, such as doctor visits, hospital visits and stays, and emergency services (Government of Ontario, n.d.). There are also provincial programs available to support families who have a member with a disability (Ministry of Children, Community and Social Services of Ontario, n.d.), as well as financial assistance (Ontario Disability Support Program Act, 1997). Application processes, however, can be onerous, waitlists can be long, and it can be difficult to access these supports, particularly when barriers to communication are present.

Parents of children who have a disability face unique demands and challenges compared to parents of children who do not have a disability (Emerson, 2003; Isa et al., 2016; Kyrkou, 2018; McStay et al., 2014; Perry, 2004; Small 2010), and quality of life is generally lower among the former group (Benjak, 2011; Gardiner, 2014; McStay et al., 2014). Raising a child with a disability comes with considerable parental stress, and the psychological well-being of caregivers

is at-risk (Emerson et al., 2004; Isa et al., 2016). Having a child with a disability can also cause strain in sibling relationships, contributing to family discord (Allison & Campbell, 2015; Kyrkou, 2014). Chronic fatigue resulting from frequent appointments and advocating for services is a major issue for parents, particularly mothers (Kyrkou, 2018). Further, caregivers often lack time to dedicate to other family members' needs, as well as their own interests. Respite services are of great benefit to this group, but can be difficult to access (Brown, MacAdam-Crisp et al., 2006; Isa et al., 2016). A mother in one study commented, "We do get respite but we use this time to do the cooking, cleaning and grocery shopping" (Brown, MacAdam-Crisp et al., 2006). The health of all individuals in a family is critical to both individual and family quality of life (Kyrkou, 2014), and families with a member who has a disability are at an increased risk of developing health problems (Benjak, 2011; Brown, MacAdam-Crisp et al., 2006; Emerson, 2003; Kyrkou, 2018; Lunskey et al., 2007). Nevertheless, one Canadian study found that overall family health was perceived as satisfactory in the majority of the sample, and was a significant predictor of family quality of life (Brown, MacAdam-Crisp et al., 2006).

Families with a member who has a disability experience considerable financial burden and strain (Emerson, 2003; Isa et al., 2016; Lundy, 2012). Providing basic necessities can be costly, and much-needed financial services can be difficult to obtain (Isa et al., 2016; Lundy, 2012). In the US and elsewhere, it is well documented that lower socioeconomic status predicts lower FQOL (Emerson et al., 2004; Enwefa et al., 2006; Lundy 2012; Meyers et al., 2000; Park et al., 2002; Wang et al., 2004). One Canadian study described above, however, found that while Financial Well-Being was rated highest in Importance, no mean scores on the other dimensions in this domain were below 3 on the 5-point scale (Werner et al., 2009). The researchers viewed

it as concerning that the other domain scores were lower than the Importance score, since low income negatively impacts the resources available to families, however, no information specifically about participant income was reported in this study, and furthermore, the sample was very small. That the researchers conceptualize scores of 3+ on the 5-point scale as being “low” suggests that distributions of ratings were negatively skewed in their study, that is, most domains were rated highly across most dimensions. Indeed, of the 54 mean scores calculated (reflecting nine domains across six dimensions), only three were below 3, the lowest being 2.47.

With regards to services, in their study of low-income families in the US, Samuel and her colleagues found that more than half did not receive the services they require. Almost all rated services as being important, but only half were satisfied with the support they were receiving (Samuel, Hobden et al., 2012). Lack of awareness of existing services and long waitlists contribute to families’ challenges in this domain (Lunsky et al., 2007), and there is evidence in Canada and elsewhere that ineligibility for services is problematic, and that satisfaction with services, even when they are received, is low (Brown, MacAdam-Crisp et al., 2006). One Canadian study evaluating barriers to services, however, found that parents of children with DD do access a variety of services, though many also believe that there are services they require and are not receiving (Rourke & Perry, 2017).

Health, finances and disability services share a complex interaction in families with members with DD; health concerns in the family can necessitate additional services being needed, which can increase a family’s financial burden, which can negatively impact a family’s health, and so forth. The three domains of the FQOLS-2006, Health of the Family, Financial Well-Being and Support from Disability-Related Services have been found to be important to families’ quality of life, but there are conflicting results about their respective contributions.

This may, in part, be due to culture-bound elements of FQOL. Some research has been conducted in Canada to examine these domains, but much of the research has employed small samples or has combined Canadian data with that from other countries. Furthermore, most research about the FQOLS-2006 has focused on the six questions in Section B for each domain, related to the measure's six dimensions. Little study has been dedicated to the general information questions in Section A, and how they might relate to FQOL. Thus, the second area of investigation in the present study was to analyze participants' responses to general information questions in the A Sections of the Health, Financial Well-Being, and Support from Disability Services domains, and to investigate their relationship with domain-level FQOL as measured in the B Sections of each of these domains.

Finally, various factors regarding family constellation are known to have an impact on family quality of life. Questions in the *About Your Family* part of the FQOLS-2006 tap into some of these factors, for example, asking respondents whether they belong to a one-parent or two-parent family. It is well-documented that single parents have unique and additional stressors beyond those experienced by two-parent teams (Gottlieb, 1997; Hernández et al., 2009; Ihinger-Tallman 1995; Small, 2010). Single parents are tasked with meeting both the emotional and financial needs of the family, and single parents of families with a member who has a disability must do so while also coping with the additional challenges this presents (Gottlieb, 1997; Parish et al., 2012; Small, 2010). Previous research has suggested that single mothers, compared to married mothers, are generally more prone to stress and depression (Small, 2010). A US study compared married mothers of children with DD, single mothers of children with DD and single mothers of children without DD on financial well-being. The researchers found that single mothers of children with DD had markedly worse financial well-being with regards to both

income and assets, than the other two groups of mothers (Parish et al., 2012). In a study done in Mexico, women from single-parent families were found to have lower quality of life, lower income, and greater depression than women from two-parent families (Hernández et al., 2009).

Another aspect of family makeup that may impact family quality of life is the number of individuals in a given family who have a disability. In the *About Your Family* part of the FQOLS-2006, respondents are asked how many individuals in their family have a disability. If family quality of life is lower when one member of a family has a disability, it stands to reason that FQOL may be negatively correlated with the number of family members with a disability; as the care demands increase, the strain on a family may multiply with additional members who have a disability, further lowering FQOL. Little research has been done to look at this topic, however. In one study, a mother offered, “The issues become more complex when there is more than one child in the family with a disability”; and given “the nature of autism . . . it is very hard to go anywhere with the kids.” (Brown, MacAdam-Crisp et al., 2006). Another study, however, using a Canadian sample and employing the Beach Centre Family Quality of Life Scale, concluded that having more than one child with DD has no major impact on FQOL compared to having only one child with DD (Patterson et al., 2018).

Our third area of investigation was to compare domain-level FQOL between families of different constellations, specifically one-parent vs two-parent families, and families with one vs more than one individual with a disability, among our sample of urban families in Ontario, using the FQOLS-2006.

To summarize, three areas of investigation were examined across three studies:

- 1) Is the factor structure of the FQOLS-2006 valid for use with urban families in Ontario?
- 2) How do responses to Section A questions in three key domains, the Health of the Family, Financial Well-Being and Support from Disability Services, relate to domain-level FQOL ratings in the B Sections of these domains?
- 3) How do FQOL ratings of families of one-parent vs two-parent families, and families with one vs more than one member with DD compare across the FQOLS-2006's nine domains?

Methods

Participants

The sample for these analyses consists of 169 Canadian respondents to the FQOL-2006. Data were collected in Toronto, Canada's largest urban centre, from two community agencies (MukiBaum Accessibility Centre and Surrey Place Centre), from the local Down Syndrome Association, and through a study conducted at York University as part of a Canadian research program called Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS). All respondents provided informed consent before completing the survey, and the current study was approved by York University's Ethics Review Board. Survey respondents were primarily mothers, and the majority of individuals with DD were male. Some primary characteristics of participating families and family members with DD are illustrated in Table 1.

Table 1

Characteristics of participants

Demographics	
Total number of families	169
Total number of individuals with DD	192
Gender (%)	
Male	68.8
Female	31.3
Mean age of individual with DD (years)	16.8 (SD = 9.5)
Primary caregiver (%)	
Mother (biological, step and adoptive)	79.9
Father	13.0
Mother and Father/Parents	3.6
Other	3.6

Materials

The FQOLS-2006 was completed by all participants in the current study. The instructions explain that the survey may be completed by the main caregiver (self-administration by a parent, sibling, spouse or life partner, or other family member) of a person with an intellectual or developmental disability, or completed by a practitioner or researcher in an interview format with the main caregiver (face-to-face administration). The survey allows for collection of data from families with up to three members with disabilities.

The first part of the FQOLS-2006, *About Your Family*, asks questions about family composition and characteristics. These include questions about the relationship of the respondent to the individual with DD, number of individuals in the family with DD, other family members, specific diagnoses, level of communication, level of support required, and other people involved in the family's day to day life.

The nine parts of the FQOLS-2006 that follow pertain to each of the measure's nine domains of family life: Health of the Family, Financial Well-Being, Family Relationships, Support from Other People, Support from Disability Related Services, Influence of Values, Career and Preparing for Careers, Leisure and Recreation, and Community Interaction. Each of these nine parts of the measure contains sections A and B. Section A gathers general information about the domain in question. For instance, respondents are asked about health conditions in the family, family income, family supports, cultural/spiritual beliefs, education and careers, and family activities. For each domain, Section B consists of the same six questions, measured using 5-point Likert-type scales. These six questions reflect the six dimensions used to evaluate each domain; Importance (the importance families place on a given domain), Opportunities (the degree to which families view options as being available to them), Initiative (the degree to which families take advantage of the options), Attainment (the degree to which families perceive they are able to attain things they want or need), Stability (the degree to which a family's circumstances with regards to a given domain may improve or worsen in the near future), and Satisfaction (the degree to which families are satisfied with their current state within a given domain). The dimensions represent issues that are pertinent to each of the nine domains. The final part of the survey is called *Overall Family Quality of Life* and asks respondents for their general impressions. This part consists of five open-ended questions, allowing respondents to elaborate on their responses, and two questions requiring responses on 5-point Likert-type scales. The latter two questions ask the respondent 1) to rate their overall family quality of life, and 2) to rate their overall satisfaction with their family's quality of life.

Data Collection

One-hundred forty-six of the participating caregivers completed the survey via individual face-to-face administration with trained research assistants. Research assistants read the questions and recorded the participants' responses. Twenty-three participating caregivers responded to the survey in a group format; caregivers convened in a large, quiet room and completed the questions individually, with a researcher trained in the administration of the survey available for assistance at all times.

The data were captured in two separate databases (one consisting of data collected through MukiBaum, and the other consisting of data collected through York University and Surrey Place Centre). Permission was granted to use the data for the purposes of the current research, and the databases were manually amalgamated into one master database in the Statistical Package for Social Sciences (SPSS) (Version 26).

Study 1

Data Analysis

Study 1 pertains to our first area of investigation regarding the factor structure of the FQOLS-2006. Since the domains and factors of the FQOLS-2006 are well supported by research, we conducted Confirmatory Factor Analysis (CFA) rather than Exploratory Factor Analysis. This study follows from the 2012 study (Isaacs et al., 2012), where data sets from three countries (Australia, Canada, and the USA), were collapsed and analyzed together using CFA. Here, we conducted CFAs with a larger, uniquely Canadian sample, to determine the usefulness of the tool with urban families in Ontario. Our two research questions were as follows:

- 1) Is the domain-level factor structure of the FQOLS-2006 valid?

2) Is the overall FQOL factor structure of the FQOLS-2006 valid?

Factor analysis was originally devised for use with continuous variables (Flora, 2018), however the present study models responses to individual Likert-type items from the FQOLS-2006, resulting in ordinal categorical variables. Treating item-level (categorical) variables as continuous variables has been demonstrated to be problematic (Flora et al., 2012), especially when the items have five or fewer response categories, because categorical variables' interrelations are nonlinear (Flora, 2018). In such cases, CFA models are better fit to polychoric correlation matrices, which do not assume linear interrelations, rather than to observed product-moment covariance matrices, which do, and are commonly used for modeling continuous variables.

The dimension items on the FQOLS-2006 are all measured using 5-point Likert-type scales, resulting in five, ordered response categories. Thus, when examining the measure's factor structure, models were fit to polychoric correlation matrices, and diagonally weighted least squares (DWLS) were used to estimate model parameters. CFAs were conducted using R and R studio software. To correct for inaccuracies resulting from the fact that DWLS does not include the information from the full weight matrix, R generates robust model fit statistics and standard error estimates using a procedure analogous to the Satorra-Bentler scaled chi-square (Savalei & Rhemtulla, 2013) commonly used with continuous data. We referred to these robust fit statistics to guide our analyses.

Although chi-square is commonly reported as a fit index in CFA, there is some question as to the appropriateness of using this test in structural modeling since 'success' depends on failing to reject the null hypothesis; the chi-square tests that the model does not fit the data, and

we want to know if the model does fit the data, so conceptually, the chi-square test is not estimating what is needed. Nevertheless, we opted to report chi-square statistics, mainly because they are the basis for most other fit statistics. We chose also to examine the RMSEA and CFI, two non-centrality-based indices, which are popular alternatives to the chi-square test. We also report the TFI, a relative fit index, which compares the model tested to a null model in which there are no latent variables. Finally, we report the SRMR, an absolute fit index, meaning that it does not use an alternative model as a basis for comparison. We decided to report the SRMR specifically because, unlike other absolute fit indices, it is not a simple transformation of chi-square, but rather, reflects the standardized difference between a model's predicted and observed correlations (Kenny, 2015). By considering statistics evaluating various aspects of model fit, we aimed to determine the best possible fitting model overall. With regards to interpreting fit indices, RMSEA values under .05 denote a close-fitting model, values between .05 and .08 indicate acceptable fit, and values between .08 and .10 indicate mediocre fit. RMSEA values above .10 indicate poor fit. CFI and TLI values above .95, and SRMR values under .08, denote close model fit.

Finally, missing values in the data set were addressed using the method of full-information maximum likelihood (FIML) estimation, where all information available from each case contributes toward the estimation of the overall model.

Results

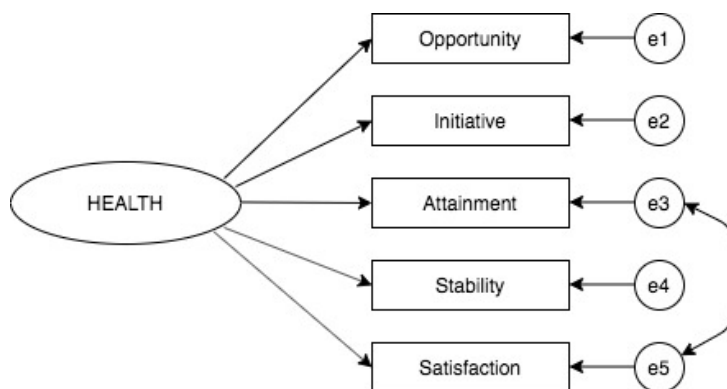
CFA assumes that variables are normally distributed, so to begin, frequency distributions of each dimension, for each domain were examined. Like Isaacs et al. (2012), we found in our Canadian sample that the Importance distributions for all nine domains were negatively skewed;

participants rated all domains very high in importance. This type of skew cannot be corrected using data transformation, and nonnormality biases and invalidates the results of these statistical analyses, so the Importance dimension was excluded from our CFAs.

To investigate our first research question, the factor structure of each domain of the FQOLS-2006 was examined in a series of nine, one-factor CFA models. In each model, the FQOL domain was treated as the latent construct, and the five remaining dimension scores were treated as indicators, to determine if the dimension items validly measure the nine domains. Werner et al. (2009) found that Attainment and Satisfaction were highly correlated within most domains. Furthermore, the sum of Attainment and Satisfaction scores is commonly treated as an outcome variable, and used as a measure of domain-level FQOL, suggesting that these are related concepts. It makes conceptual sense that the items are related; without attainment, satisfaction in a given domain seems less likely. For this reason, rather than freely estimate the models, the first iteration of our nine domain models specified error covariance between Attainment and Satisfaction. An example of a domain-level factor structure, using the Health of the Family domain as the latent construct to illustrate, is depicted in Figure 1.

Figure 1

Factor structure for Health of the Family domain



The results of the first model specification for each domain can be found in Table 2. The models for the Health, Family, Values and Community domains fit the data very well. The remaining five domain models, for Finance, Support from Others, Support from Services, Careers and Leisure, had problematic fit indices.

Table 2

Domain models with Attainment and Satisfaction error terms covaried

Model 1: Att~Sat					
Domain	<i>p</i> (chi-square)	RMSEA	CFI	TLI	SRMR
Health	.451	0.000	1.000	1.005	0.027
Finances	.036 ^p	0.098 ^p	0.992	0.979	0.044
Family	.313	0.034	0.999	0.998	0.033
Others	.004 ^p	0.129 ^p	0.986	0.966	0.058
Services	.002 ^p	0.139 ^p	0.952	0.880 ^p	0.071
Values	.575	0.000	1.000	1.003	0.027
Careers	.002 ^p	0.138 ^p	0.988	0.970	0.044
Leisure	.000 ^p	0.158 ^p	0.984	0.960	0.075
Community	.114	0.072	0.997	0.992	0.036

^p Problematic fit indices.

Model modifications should be driven by theory. Most CFA software, however, including R, generates modification indices, which indicate the least amount by which model fit will improve by covarying various error terms. This information can be useful to guide model specification, provided the error covariances make theoretical sense. Inspection of modification indices revealed the error covariances that would yield the greatest improvement in model fit for each domain. We considered these as we made decisions about model specification, described presently. The results of the final, well-fitting models can be found in Table 3.

In the Finances domain, there appears to be a systematic error in measuring Opportunities and Initiative. A person high in initiative may find opportunities to make money through their efforts to do so. Alternatively, if a person does not perceive there to be an opportunity to earn enough money to do the things their family wants, they may be unmotivated to take initiative to work toward that goal. In the Support from Services domain, modification indices revealed that the error covariance that would yield the greatest improvement in model fit was between Initiative and Stability. However, since prior research has found the FQOLS-2006's dimensions to be correlated, with the exception of the Stability dimension (Werner et al., 2009), we opted not to covary the Stability error term. Instead, we added the error covariance yielding the second-best improvement in model fit, between Opportunity and Satisfaction. The model still did not fit the data well. Inspection of modification indices from this second specification resulted in our covarying the error terms of Opportunity and Attainment, which produced close model fit (Table 3). Without perceiving opportunities to access disability-related services, a respondent will not likely report attaining them, and it is unlikely they will report being satisfied with services they do not feel they have had the opportunity to benefit from. Indeed, a path analysis study from 2015 revealed that Opportunities had the highest total effect on Attainment and Satisfaction, suggesting a strong relationship between these dimensions (Isaacs et al., 2011). In both the Careers and Leisure domains, modification indices indicated that covarying the error terms of Initiative and Attainment would improve model fit the most. For Careers, this covariance resulted in close model fit. The degree to which individuals feel they have been able to attain the education or career they want is likely related to the efforts they make to develop their education or career. For Leisure, the model still did not fit well. Additionally covarying the error terms for Initiative and Satisfaction resulted in close model fit in the Leisure domain (Table 3). The

effort a family makes to take part in leisure activities is likely related to the degree to which they actually engage in leisure activities, and feeling as though they have made an effort, or not, likely affects their sense of satisfaction. Similarly, with regards to covarying error terms for Initiative and Satisfaction in the Support from Others domain, the degree to which a family makes efforts to recruit support from other people likely affects their sense of satisfaction with the support they receive.

There is little to suggest that relationships between the dimensions are domain-specific. For example, the idea that initiative ratings covary with attainment ratings makes conceptual sense across all domains. For this reason, while there appears to be some conceptual redundancy between the dimensions, the specific model modifications that improved our model fit are conceptualized as being systematic measurement error, idiosyncratic to our data set.

Table 3

Domain models with Attainment and Satisfaction and domain-specific error covariances

Model 2: Att $\sim$ Sat, Additional Error Covariances						
Domain	<i>p</i> (chi-square)	RMSEA	CFI	TLI	SRMR	Additional Error Covariances
Health	.451	0.000	1.000	1.005	0.027	
Finances	.496	0.000	1.000	1.003	0.019	Opp $\sim$ Init
Family	.313	0.034	0.999	0.998	0.033	
Others	.107	0.079	0.996	0.987	0.044	Init $\sim$ Sat
Services	.270	0.043	0.998	0.988	0.029	Opp $\sim$ Att, Opp $\sim$ Sat
Values	.575	0.000	1.000	1.003	0.027	
Careers	.126	0.075	0.997	0.991	0.028	Init $\sim$ Att
Leisure	.191	0.063	0.999	0.994	0.038	Init $\sim$ Att, Init $\sim$ Sat
Community	.114	0.072	0.997	0.992	0.036	

Next we sought to evaluate measures of effect size. We examined factor loading estimates to determine the strength of the relationships between the latent constructs (the domains) and the observed variables (the dimension scores) in our final models. To set the scale of the latent variables, we had constrained the latent variable variances equal to 1 for each domain model. In our interpretation of results, we refer to the completely standardized factor loading estimates (λ^*), where a one-standard deviation increase in the latent variable predicts a λ^* -standard deviation increase in the observed variable. Table 4 depicts the factor loading estimates for the final, well-fitting models for each domain.

Table 4

Completely Standardized Factor Loading Estimates for Model 2

Model 2 – Factor Loading Estimates					
	Opportunity	Initiative	Attainment	Stability	Satisfaction
Health	0.41	0.55	0.66	0.31	0.60
Finances	1.83	0.51	0.36	0.13	0.36
Family	0.64	0.96	0.84	0.20	0.80
Others	0.70	0.85	0.87	0.13	0.71
Services	0.12	0.85	0.33	-0.25	-0.01
Values	0.73	0.88	0.82	0.24	0.65
Careers	0.88	0.65	0.77	0.39	0.78
Leisure	2.18	0.23	0.32	0.12	0.28
Community	0.64	0.70	1.09	0.27	0.78

In the Health domain, the latent variable shared the strongest relationship with Attainment, Satisfaction and Initiative, with factor loading estimates above 0.5 for each. Factor loading estimates for Opportunity and Stability were lower. In the Finances domain, Opportunity shared a notably strong relationship with the latent variable, suggesting that

perceiving oneself to have (or not have) the opportunity to earn enough money has the greatest influence on financial FQOL in our sample. Initiative also yielded a factor loading estimate above 0.5, whereas all other factor loading estimates were lower. In the Leisure domain too, to an even greater degree, Opportunities shared a very strong relationship with the latent variable, suggesting that the perception of having the opportunity to engage in leisure activities has the greatest influence on FQOL in this domain. Again, these results are consistent with the path analysis that found the Opportunities dimension to be most strongly related to Attainment and Satisfaction (Isaacs et al., 2011). All other factor loadings in the Leisure domain were much lower. In the Family domain, Initiative was demonstrated to have the strongest relationship with the latent variable, and all other factor loading estimates except for Stability were over 0.5. In the Support from Others domain, Attainment was found to have the strongest relationship with the latent variable, and all other factor loading estimates except for Stability were over 0.5. In the Support from Services domain, the latent variable was only found to be strongly related to Initiative, shared a small inverse relationship with Stability, and no relationship with Satisfaction. This suggests that the degree to which a family makes efforts to obtain the disability-related services they need has the strongest association with FQOL in that domain. That Satisfaction was found to have almost no relationship with FQOL in the Services domain is likely a product of sampling error, though more research would be required to fully explain this finding. In both the Values and Careers domains, all factor loading estimates except for Stability were over 0.5. Finally, in the Community domain, Attainment shared a notably strong relationship with the latent variable, indicating that the degree to which families actually interact with people and places in their community has the greatest association with FQOL in this domain. All other factor loading estimates except for Stability were over 0.5 in the Communities

domain. Overall, the most notable finding was that Stability had the weakest relationship with the latent variable across eight of the nine domains.

Since our models fit the data well and we could be confident that the factor structure of the models was sound, we were most interested in measures of effect size. Still, statistical software, including R, generates p values to evaluate the significance of pathways in SEM models, so we briefly considered these as well. Evaluation of p values calculated on our final model specifications in Table 3, revealed that at $p=.05$, all dimension pathways were significant in five of the models (Health, Family, Values, Careers and Community), and all pathways except for Stability were significant in the Support from Others domain. In the remaining three models (Finance, Support from Services and Leisure), several pathways were non-significant; in the Finance domain, only the Opportunity pathway was significant, in the Support from Services domain, only the Initiative and Attainment pathways were significant, and in the Leisure domain, no pathways were significant. There are many reasons pathways may be non-significant, which do not diminish our confidence in the soundness of the factor structure evidenced by the close-fitting models. Indeed, p values are highly influenced by extraneous factors such as missing data, sampling error and, most notably, sample size. With too small a sample, pathways can be non-significant despite substantively meaningful effects, and with too large a sample, pathways can be significant even when associations between variables are negligible. With a large enough sample, all model pathways would be significant.

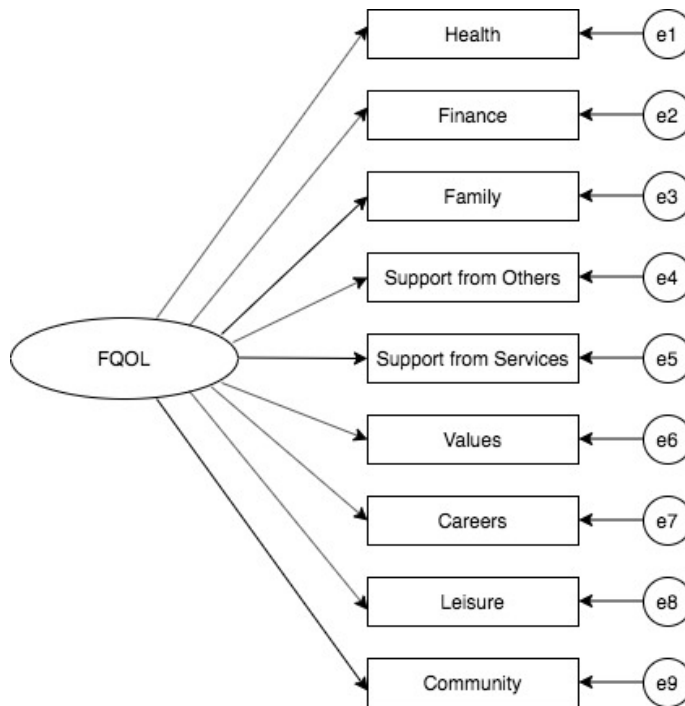
Overall FQOL

To address our second research question in Study 2, we analyzed the overall FQOL factor structure of the FQOLS-2006. A CFA was conducted to test whether the latent construct of

FQOL is reliably measured by the nine domains, using mean scores of participants' responses to each of the five dimension questions (all but Importance), as indicators. This model is depicted in Figure 2.

Figure 2

Factor structure of overall FQOL



The results of the freely estimated model can be found in Table 5. The model fit the data very closely according to all fit indices.

Table 5

Overall FQOL model, freely estimated

Overall FQOL Model				
<i>p</i> (chi-square)	RMSEA	CFI	TLI	SRMR
.882	0.000	1.000	1.077	0.037

Table 6 displays the completely standardized factor loading estimates for each domain. All domain pathways were significant at $p=.05$. With regards to effect size, relationships with the latent variable of FQOL were comparable across domains, the factor loadings ranging from 0.32 (Values) to 0.65 (Leisure).

Table 6

Completely Standardized Factor Loading Estimates for Overall FQOL Model

Overall FQOL Model – Factor Loading Estimates								
Health	Finances	Family	Others	Services	Values	Careers	Leisure	Community
0.58	0.38	0.48	0.47	0.42	0.32	0.38	0.65	0.63

Study 2

Data Analysis

Studies have been conducted to evaluate the FQOLS-2006's psychometric properties, the focus mainly being on Section B of each domain. Little has been written about Section A. Specifically, with our Canadian sample, we were interested in examining the domains of Health of the Family, Financial Well-Being and Support from Disability Related Services, since they are

likely influenced by a country's healthcare system and social services. Section A of the Health of the Family domain asks about physical and/or mental health concerns within the family, and barriers to accessing healthcare. Section A of the Financial Well-Being domain asks about total family income, financial supports, basic financial needs, and disability-related expenses. Section A of the Support from Disability Related Services domain asks about available services, services used, services needed and barriers to service. The aim of our second area of investigation was to determine how respondents' reports regarding the status of their family's health, finances and disability services relate to their overall family quality of life ratings in these domains. We also sought to explore family characteristics of respondents who reported high FQOL ratings despite reporting difficult circumstances in Section A.

First, we explored associations between general information questions in Section A and overall domain-level FQOL in Section B, using crosstabulation. As described above, questions one through six in Section B for each domain pertain to the measure's six dimensions, and each is measured using a 5-point Likert-type scale (e.g., 'hardly at all' = 1, 'a little' = 2... 'a great deal' = 5). Overall FQOL for each domain was calculated by summing participants' responses to questions 4 and 6 of Section B of a given domain, measuring Attainment and Satisfaction, respectively, resulting in domain-level FQOL scores out of 10. Henceforth, these scores will be referred to as Health FQOL, Finance FQOL and Services FQOL.

In the Health domain, we performed three crosstabulations. First, we cross-tabulated Health FQOL with "Yes" and "No" responses to Question 1a of Section A, asking if there are major physical and/or mental health concerns for the family member(s) with DD. Next, we cross-tabulated Health FQOL with "Yes" and "No" responses to Question 2a of Section A, asking if there are major physical and/or mental health concerns with other members of the

family. Finally, we cross-tabulated Health FQOL with responses to Questions 1a and 2a of Section A, combined, resulting in three groups: families reporting no health concerns, families reporting health concerns with either family member(s) with DD or other family members, and families reporting health concerns with both family member(s) with DD and other family members.

In the Finance domain, we performed two crosstabulations. First, we cross-tabulated Finance FQOL with responses to Question 1a of Section A. The question, “In your country, how would your total family income, including all pensions, be described?”, is rated on a 5-point Likert-type scale, producing five groups: well below average, below average, average, above average, and well above average. Next, we cross-tabulated Finance FQOL with responses to Question 5a of Section A. This question asks respondents to rate how many of their basic needs (for example, food, clothing, adequate housing) are met by their family income, on a 5-point Likert-type scale, resulting in five groups: none, a few, some, most, and all.

In the Services domain, we performed one crosstabulation. We cross-tabulated Services FQOL with “Yes” and “No” responses to Question 3a of Section A, asking if there are disability related services the family needs and is not currently receiving.

Following the crosstabulations, we performed chi-square tests to quantitatively compare groups on domain-level FQOL. For these, we collapsed the FQOL data to create “low” and “high” FQOL groups (the cutoffs for which are described below), for each of the three domains in question (Health, Finance and Services). In the Health domain, we performed two 2x2 chi-square analyses to look at differential Health FQOL responding (“low” vs “high”) among 1) participants reporting “yes” and “no” to health concerns with person with DD, and 2) participants reporting “yes” and “no” to health concerns with other family members. We

conducted a third chi-square analysis to compare differential Health FQOL responding (“low” vs “high”) across three groups of respondents: those reporting health concerns both with family members with DD and other family members, those reporting health concerns either with family member with DD or other family members, and those reporting no health concerns in the family.

In the Finance domain, for the question about perceived family income, we collapsed the “below average” and “well below average” groups, and we collapsed the “above average” and “well above average” groups. This formed three groups: “below average”, “average” and “above average”. We compared these three groups across “low” and “high” Finance FQOL using a 2x3 chi-square analysis. We also conducted a 2x2 chi-square analysis to compare respondents who reported having their basic needs met (those who reported “all” to the question about basic needs) with those who reported not having their basic needs met (those who reported “most”, “some”, “a few” and “none”), across “low” and “high” Finance FQOL.

In the Services domain, we performed one 2x2 chi-square analysis to compare groups of participants responding “yes” and “no” to whether there are services they require and are not currently receiving, across “low” and “high” Services FQOL.

In addition to the crosstabulations and chi-square analyses, for each domain in question, we performed qualitative investigations of family characteristics of a subset of respondents in each group who reported high domain-level FQOL despite reporting difficulties in Section A. Responses to demographic questions in the *About Your Family* part of the questionnaire, as well as responses to other questions in the A Sections of the domains in question were explored, to describe these subsets of respondents.

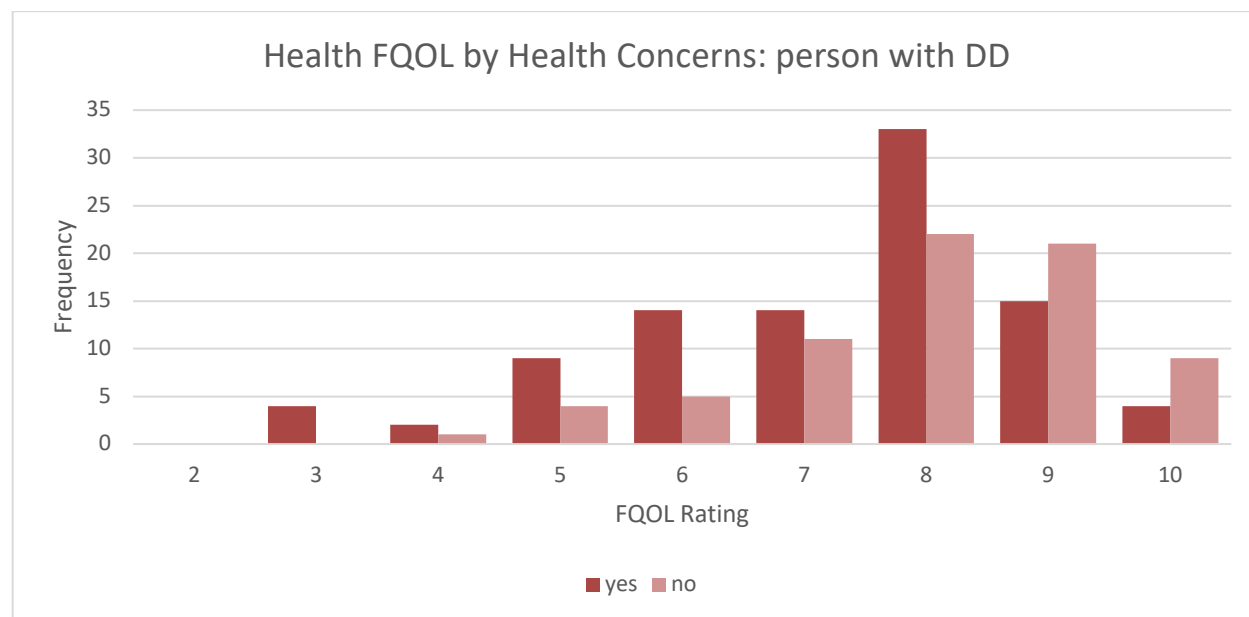
Results

Health

The results of the crosstabulation of Health FQOL with health of family members with DD are displayed in Figure 3. No one in either group reported Health FQOL lower than 3, and the lowest score among families where the individual with DD did not have health concerns was 4. Most scores for both groups cluster right of centre of the FQOL scale, but generally speaking, higher FQOL scores were more likely when health concerns among family members with DD were absent. The mode for both groups was 8, representing 35% ($n=33$) of the “yes” group and 30% ($n=22$) of the “no” group. Health FQOL scores of 5 and below make up 16% of the “yes” group and only 7% of the “no” group, whereas scores above 8 make up 41% of the “no” group and only 20% of the “yes” group.

Figure 3

Crosstabulation of Health FQOL with health of person with DD



A chi-square test of independence was performed to quantitatively investigate the relationship between Health FQOL and health concerns with family members with DD. Table 7 contains the data: Health FQOL collapsed into “low” (responses 6 and below) and “high” (responses 7 and above) groups, by “yes” and “no” responses regarding health concerns of family members with DD. We defined the “low” and “high” Health FQOL groups in this way (6 or less vs 7 or more) because the distributions tended to be negatively skewed; most people reported fairly high Health FQOL. Since no participants in either group reported Health FQOL less than 3, the range of each group was 3 (“low” = 3-6 and “high” = 7-10). The relationship between these variables was significant, $\chi^2(1, N = 168) = 6.56, p = .010, V = .20$. Respondents with health concerns with family members with DD were more likely than those without to report low Health FQOL, and the Cramer’s V of .20 indicates a strong association. Indeed, 31% ($n=29$) of participants in the “yes” group reported low Health FQOL compared to only 14% ($n=10$) in the “no” group.

Table 7

Health FQOL by health of person with DD, collapsed

		Health Concerns: person w DD				Total
		yes	%	no	%	
Health FQOL	low	29	31	10	14	39
	high	66	69	63	86	129
Total		95	100	73	100	168

The results of the crosstabulation of Health FQOL with health of family members other than those with DD are displayed in Figure 4. Again, no one in either group reported Health FQOL lower than 3. Most scores for the “yes” group cluster right of centre of the FQOL scale

but the distribution of “no” responses is considerably negatively skewed. Again, the mode of each group is 8. Health FQOL scores between 5 and 7 make up 48% of the “yes” group and only 17% of the “no” group, whereas scores above 8 make up 45% of the “no” group and only 15% of the “yes” group.

Figure 4

Crosstabulation of Health FQOL with health of other family members

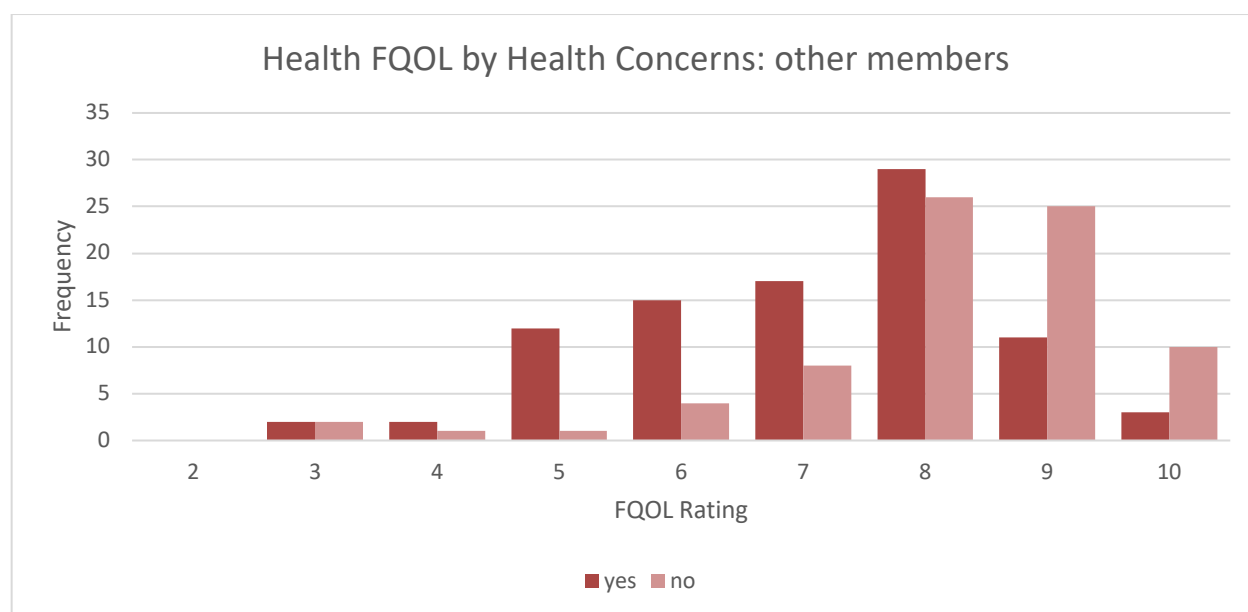


Table 8 contains the data used for the chi-square test of independence: “low” (responses 6 and below) and “high” (responses 7 and above) Health FQOL groups, by “yes” and “no” responses regarding health of family members other than those with DD. The relationship between these variables was significant, $\chi^2 (1, N = 168) = 13.12, p < .001, V = .28$. Respondents with health concerns with other family members were more likely than those without to report low Health FQOL, and the Cramer’s V of .28 indicates a very strong association. Here, 34%

($n=31$) of participants in the “yes” group reported low Health FQOL compared to only 10% ($n=8$) in the “no” group.

Table 8

Health FQOL by health of other family members, collapsed

		Health Concerns: other members				Total
		yes	%	no	%	
Health FQOL	low	31	34	8	10	39
	high	60	66	69	90	129
Total		91	100	77	100	168

A total of 60 respondents reported health concerns with both family members with DD and with other family members, 64 Respondents reported health concerns with either family members with DD or other family members, and 43 respondents reported no health concerns in the family. The results of the crosstabulation of Health FQOL with health of all family members combined, are displayed in Figure 5. Scores for the “both” group cluster closer to the centre of the FQOL scale, whereas scores in the “either” group tend to be higher, and scores in the “none” group tend to be higher still. The mode for the “both” group is 8, and represents 28% ($n=17$) of that group. The mode for the “either” group is 8, and represents 41% ($n=26$) of that group. The mode for the “none” group is 9, and represents 40% ($n=17$) of that group. Health FQOL scores below 8 make up 57% of the “both” group, 36% of the “either” group, and only 16% of the “none” group, whereas scores above 8 make up 58% of the “none” group, 23% of the “either” group, and only 15% of the “both” group.

Figure 5

Crosstabulation of Health FQOL with health of person with DD and health of other family members, combined

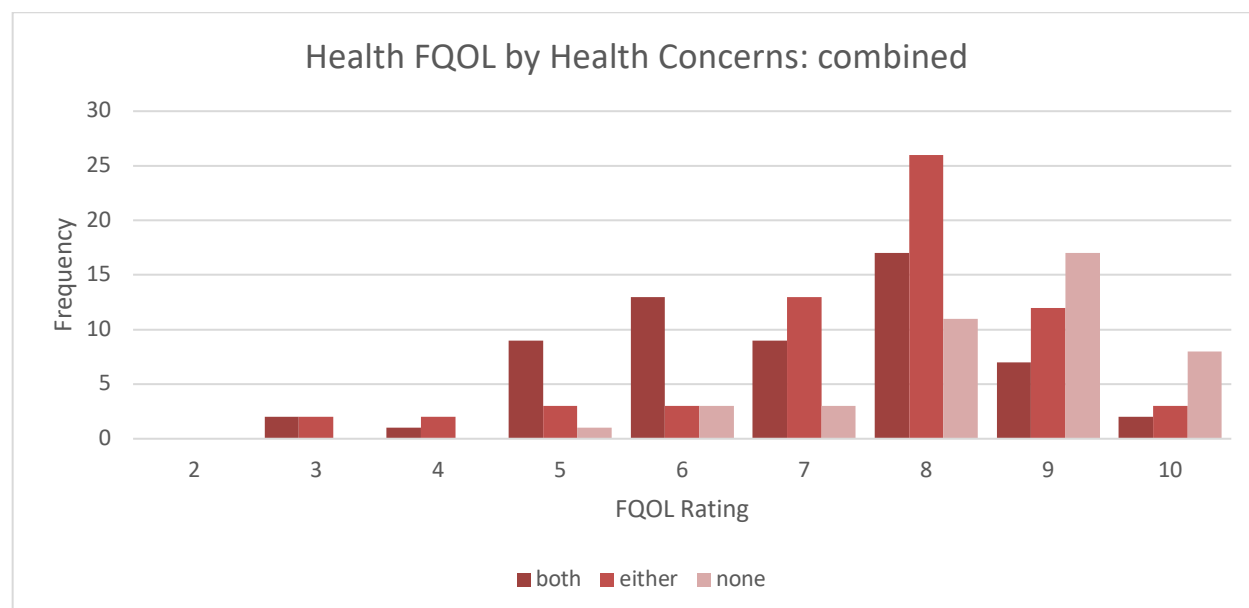


Table 9 contains the data used for the 2x3 chi-square test of independence: “low” and “high” Health FQOL groups as defined above, by “both”, “either” and “none” groups, representing participants with health concerns with both family members with DD and other family members, participants with either health concerns with family members with DD or other family members, and participants reporting no health concerns. The relationship between these variables was significant, $X^2(2, N = 167) = 18.12, p < .001, V = .33$. In light of the significant chi-square results, we proceeded to investigate the source of the difference between the groups. We calculated probability values for each group from the adjusted residuals, and compared them to an adjusted alpha, created using the Bonferroni correction. The source of the significant difference between the groups was the “both” group; respondents reporting health concerns both with family members with DD and other family members were significantly more likely to report

low Health FQOL than respondents in the other two groups, and the Cramer's V of .33 indicates a very strong association. Indeed, 42% ($n=25$) of participants in the "yes" group reported low Health FQOL compared to 16% ($n=10$) of those in the "either" group and only 9% ($n=4$) of those in the "none" group.

Table 9

Health FQOL by health of person with DD and health of other family members, combined, collapsed

		Health Concerns: combined						Total
		both	%	either	%	none	%	
Health FQOL	low	25	42	10	16	4	9	39
	high	35	58	54	84	39	91	128
Total		60	100	64	100	43	100	167

High Health FQOL with Health Stressors

Of the respondents who reported health concerns both with family members with DD and with other family members, two gave their Health FQOL a rating of 10. These two participants were captured in both prior crosstabulations where health concerns of family members with DD and health concerns of other family members were evaluated separately. Aside from these two participants, two participants who reported health concerns only with family members with DD, and one participant who reported health concerns only with other family members, also gave their Health FQOL a rating of 10. These five respondents comprise the subset of participants selected for our qualitative investigation.

An examination of the *About Your Family* section, as well as the other questions in Section A of the Health domain, revealed that the two respondents with high Health FQOL reporting health concerns both with family members with DD and with other family members, were both mothers, and both had children under the age of 18, but otherwise, they had very different family constellations. A table illustrating family characteristics of these respondents can be found in Appendix B. One reported having two family members with DD and belonging to a single-parent family. She described one child as being “more severe” than the other, and indicated a complex medical profile including diabetes, psychotic disturbance and problems with motor control. She reported that both children require disability-related support for only a few aspects of life and have some limited ability to communicate. This respondent listed the father as a caregiver, though he does not live in the home. With regards to health concerns among other family members, this respondent indicated that she, herself, has a learning disorder and “panic”. The other respondent reported having one family member with DD, and belonging to a two-parent household. Maternal and paternal grandmothers were listed as caregivers, though not living in the home. This respondent indicated that her child requires support for some aspects of life and has some ability to communicate needs and ideas. With regards to health concerns with her child with DD, she reported “undiagnosed anxiety”, and with regards to health concerns among other family members, she reported “anxiety (undiagnosed)” in the child’s twin sibling.

All three children of these two respondents were reported to have behaviour problems secondary to their primary diagnosis, and one child from each family was also reported to have mood/expression/anxiety problems. Both respondents listed themselves as the most involved person in the family, and both reported having more responsibility for the family and the member

with DD than they would like. Both respondents commented that their children require “constant supervision”.

The two high Health FQOL respondents who indicated health concerns only with family members with DD were also mothers, both from two-parent families, and both with only one family member with DD, between the ages of 18 and 30. A table illustrating family characteristics of these respondents can be found in Appendix C. Both respondents also listed secondary caregivers in the home, beyond mother and father. One of the youths was reported to have Down syndrome, and ‘speech and or language difficulties’ were the only other condition identified in the *About Your Family* section. This individual was said to require support for most aspects of life, and to have limited ability to communicate. When asked about health concerns in Section A of the health domain, the respondent reported severe “cirisis” [sic] (an additional comment provides context suggesting this is likely ‘psoriasis’). The other youth was described as having a much more complex medical profile including dementia, asthma, allergies, seizures, sensory and immune system concerns, as well as speech and language difficulties. It was reported that the latter youth “has had many health problems a lot of medical intervention”. This youth was said to require support for almost all aspects of life, and communication was limited to communicating basic needs and wants. Both respondents listed themselves as the most involved person in the family (though one reported both ‘mother and father’), and both indicated they have the amount of responsibility they like both for their family and for the member with DD.

The remaining respondent with high Health FQOL who listed only health concerns with other family members was a father of two children with DD under the age of 18, who identified his family as a two-parent family. A table illustrating family characteristics of this respondent

can be found in Appendix D. Both children are described as having complex medical profiles including heart problems, gastro-intestinal problems, reflux, and concerns regarding bone growth. However, the respondent answered ‘no’ to the question about health concerns among family members with DD in Section A of the health domain. He reported that one child requires support for some aspects of life, and the other requires support for most aspects of life, and both have limited ability for meaningful communication. When asked about health concerns among other family members, he reported that the mother of the family was recovering from a serious medical condition. The respondent reported that mother and father are the most involved, and reported that he personally has about the amount of responsibility he would like for both the family and the members with DD.

Among the subset of five respondents reporting health concerns and high Health FQOL, it was noted that all respondents reported speech and/or language difficulties secondary to the main diagnosis of the family member with DD, and three of the five also reported behaviour problems as a secondary condition. These difficulties shared by the respondents in this subset, however, are not uncommon among individuals with DD, and an informal examination of secondary conditions across other respondents in our sample confirmed that these challenges are not unique to this subset of participants.

Finance – income

Incomes were distributed fairly normally, with 65 participants reporting what they perceived to be an “average” income in their country. The results of the crosstabulation of Finance FQOL with perceived family income are displayed in Figure 6. Most Finance FQOL scores for those reporting “below average” income were 4-6 (70%, $n=31$), for those reporting

“average” income, most Finance FQOL scores were 5-8 (88%, $n=57$), and the majority of respondents reporting “above average” income rated Finance FQOL at an 8 (40%, $n=14$). The 11 respondents who reported incomes “well above average” rated Finance FQOL as 8 or higher, and all but one of the 12 respondents who reported an income “well below average” rated Finance FQOL as 5 or lower.

Figure 6

Crosstabulation of Finance FQOL with perceived income

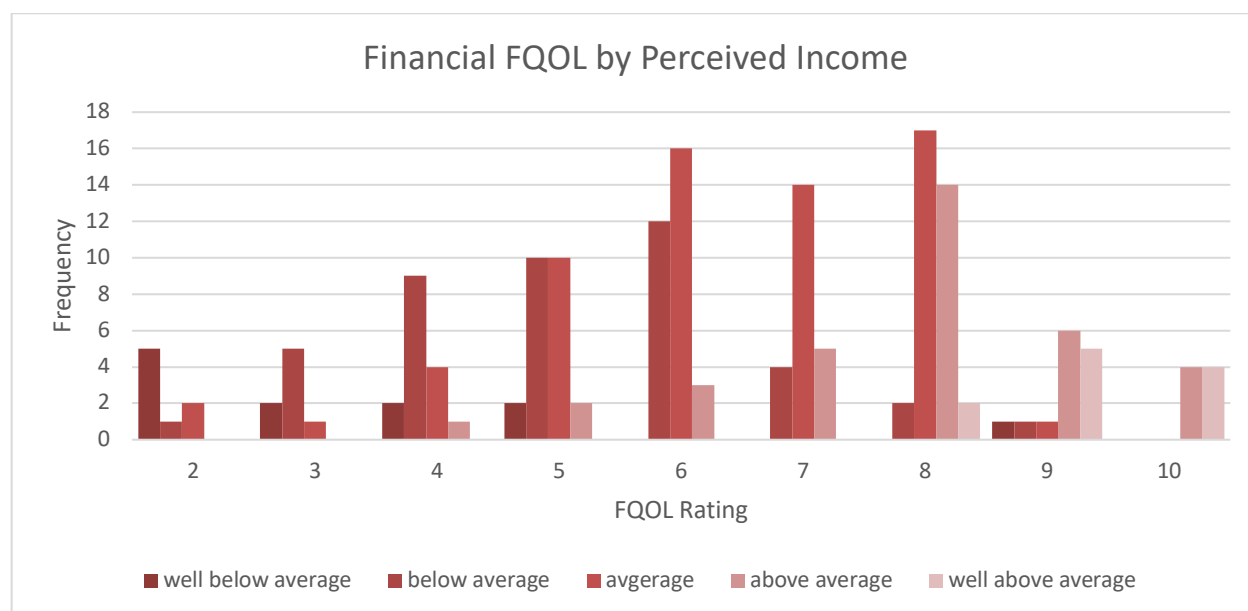


Table 10 contains the data used for the 2x3 chi-square test of independence: Finance FQOL collapsed into “low” (responses 6 and below) and “high” (responses 7 and above) groups, by “below average”, “average” and “above average” responses regarding perceived income. We defined the high and low Finance FQOL groups in this way because again, as with the Health FQOL data, there was a tendency towards negative distributions of scores. Based on this distribution of scores, we opted for a larger range in the “low” group (2-6, for a range of 4), and

the smaller range in the “high” group (7-10, for a range of 3). The relationship between these variables was significant, $X^2 (2, N = 167) = 53.52, p < .001, V = .57$. To investigate the source of the significant results, we used the same procedure described above for the 2x3 chi-square looking at combined health concerns. A comparison of the probability values to the Bonferonni corrected alpha revealed that the sources of the difference were the “below average” and “above average” groups. Participants reporting below average income were more likely to report low Finance FQOL than the other two groups, and participants reporting above average income were more likely to report high Finance FQOL than the other two groups, and the Cramer’s V of .57 indicates a very strong association. Indeed, 86% ($n=48$) of participants in the “below average” group reported low FQOL compared with 51% ($n=33$) of those in the “average group” and only 13% ($n=6$) of those in the “above average” group, whereas 87% ($n=40$) of participants in the “above average” group reported high FQOL compared with 49% ($n=32$) of those in the “average” group and only 14% ($n=8$) of those in the “below average” group.

Table 10

Finance FQOL by perceived income, collapsed

		Perceived Income						Total
		below avg	%	average	%	above avg	%	
Finance FQOL	low	48	86	33	51	6	13	87
	high	8	14	32	49	40	87	80
Total		56	100	65	100	46	100	167

In order to qualitatively explore family characteristics of participants who reported high Finance FQOL despite reporting income challenges in Section A, we opted to look at the subset of four respondents who reported incomes either below or well below average, and Finance FQOL of 8 or higher. No respondents who reported below or well below average income rated

Finance FQOL a 10, and few rated it a 9 or even an 8. Thus, to capture even a small subset of respondents for our qualitative investigation ($n=4$), we had to expand our criteria to include both the well below and below average groups, as well as Finance FQOL scores of 9 and 8. An examination of the *About Your Family* section revealed that the four respondents were a daughter, a mother, a father and ‘biological parents’, all identifying their family as being a two-parent family. Responses to other questions in the *About Your Family* part of the survey suggest that the respondent listed as “daughter”, may in fact be the parent of a daughter with DD. A table illustrating family characteristics of these respondents can be found in Appendix E. One family had two members with DD, both under the age of 18, and the rest had one, all adults over the age of 35. The most commonly occurring ‘other conditions’ among the four families were speech and language difficulties, seizures, asthma, and behaviour problems.

One family reported that the member with DD did not require support, and that the individual was able to communicate about a wide variety of topics in a meaningful way, adding that “people underestimate daughter’s ability”. This family was the only one with other family members (one sibling and one cousin) identified as being caregivers, beyond “mother and father”. The other three families reported that the family member with DD required support for some or almost all aspects of life, and that their communication was limited to expressing basic needs and wants, and some ideas.

The respondent who was a father listed ‘mother’ as the most involved person, and indicated that he personally has about the amount of responsibility he would like for both the family and the individual with DD. All other respondents listed mother and father being most involved in the family’s day to day life, and indicated that they personally had more responsibility than they would like for both the family and for the member with DD. The

respondents who were ‘biological parents’ indicated that their income was well below average, where the other three respondents indicated that their income was below average.

Finance – basic needs

The pattern of normally distributed ratings seen in response to the question about income was not observed in response to the question asking about basic needs. Here, scores were highly negatively skewed, descending in order from “all” to “none”, as can be seen in Figure 7. Indeed, 62% of respondents ($n=104$) reported having all of their basic needs met by their income. Among this group, more than one quarter of respondents ($n=28$) reported Finance FQOL of 8, and most scores (92%, $n=96$) were 5 and above. Finance FQOL scores tended to be lower for all other groups; most notably, all needs were reportedly met among 88% of those with Finance FQOL scores of 8 or higher, and among 100% of those with FQOL scores of 9 or 10. Only 7% ($n=12$) of participants reported having “none” or “a few” of their basic needs met, and Finance FQOL scores tended to be lower among these groups. The three respondents who reported having none of their basic needs met indicated Finance FQOL of 3 or lower.

Figure 7

Crosstabulation of Finance FQOL with basic needs met

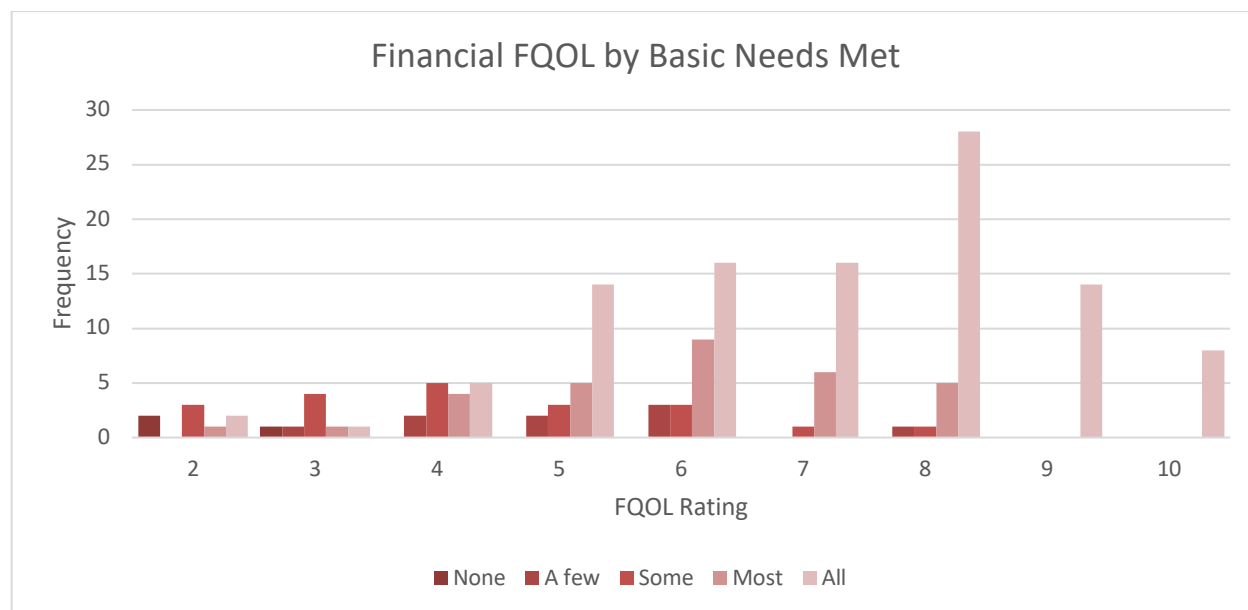


Table 11 contains the data used for the chi-square test of independence: “low” and “high” Finance FQOL groups, by “yes” and “no” responses to basic needs being met. Chi-square tests require expected cell counts of at least 5 to be meaningful. Since the majority of participants reported having all of their basic needs met, low cell count was problematic when collapsing the data. Collapsing the basic needs met groups into ‘all’ vs ‘anything less than all’ resolved this issue. And despite losing information with regards to the differences between the levels of the ‘anything less than all’ groups, we thought it nevertheless clinically relevant to collapse the groups in this way; to report having anything but *all* of one’s basic needs met (e.g., food, clothing, shelter) suggests stress and hardship. The relationship between these variables was significant, $\chi^2(1, N = 167) = 26.74, p < .001, V = .40$. Participants reporting that not all of their basic needs were met were more likely to report low Finance FQOL than participants reporting all needs met, and the Cramer’s V of .40 indicates a very strong association. A total of

63% ($n=66$) of participants reporting all needs met rated high Finance FQOL compared with only 22% ($n=14$) of those who reported that not all of their basic needs were met.

Table 11

Finance FQOL by basic needs met, collapsed

		All Basic needs met				Total
		no	%	yes	%	
Finance FQOL	low	49	78	38	37	87
	high	14	22	66	63	80
Total		63	100	104	100	167

For the purposes of qualitatively exploring family characteristics of participants who reported high Finance FQOL despite reporting challenges in Section A, we opted to look at the subset of two respondents who rated Finance FQOL an 8, despite having only a few or some basic needs met. Neither respondent was in the previously examined subset of participants with high Finance FQOL despite below average income.

An examination of the *About Your Family* section revealed that the two respondents were one mother and one father, both members of two-parent families, both with only one child with DD, both of whom were boys under the age of 10, and both of whom were reported to have speech and language difficulties. A table illustrating family characteristics of these respondents can be found in Appendix F. One boy was reported to have one sibling who lives in the home but not does act as a caregiver. This boy was said to require support for almost all aspects of life, and to have very little meaningful communication. The other boy was reported to have two siblings who live in the home, and both were listed as caregivers. This boy was said to require support for most aspects of life, and to be able to communicate basic needs and wants.

One respondent reported herself as being the most involved person in the family's day to day life, and the other respondent indicated "parents and siblings". Both respondents reported personally having much more responsibility that they would like both for the family and for the member with DD.

Services

The results of the crosstabulation of Services FQOL with the question regarding services needed/not getting are displayed in Figure 8. Two-thirds of respondents ($n=109$) reported that there are services they need and are not currently getting. The mode for Services FQOL ratings for this 'yes' group was 6, whereas the mode for the 'no' group was 8. On the upper end of the Services FQOL scale, 82% ($n=46$) of respondents in the 'no' group reported ratings of 7 or higher, and only 39% ($n=43$) of respondents in the 'yes' group did so. On the lower end, 38% ($n=41$) of participants in the 'yes' groups rated Services FQOL as 5 or lower, and only 11% ($n=6$) of the 'no' group did so.

Figure 8

Crosstabulation of Services FQOL with services needed/not getting

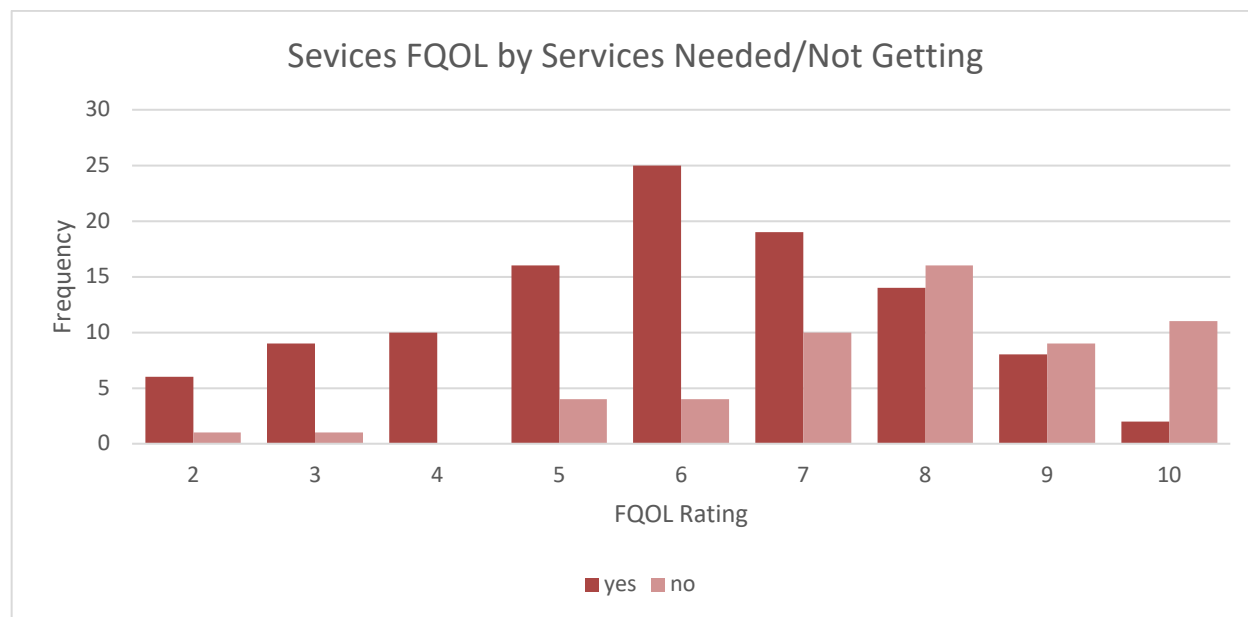


Table 12 contains the data used for the chi-square test of independence: Services FQOL collapsed into “low” (responses 6 and below) and “high” (responses 7 and above) groups, by “yes” and “no” responses regarding services needed/not getting. We defined the high and low Services FQOL groups in this way for the same reasons described above for the Health and Finance data; more scores overall fell to the right of centre of the scale so we opted for the range of the “low” group to be the wider, and that of the “high” group to be the narrower. The relationship between these variables was significant, significant, $\chi^2 (1, N = 167) = 27.14, p < .001, V = .41$. Respondents reporting that there were services they required and were not receiving were more likely to report low Services FQOL than participants not reporting this, and the Cramer’s V of .41 indicates a very strong association. Indeed, 61% ($n=66$) of “yes”

respondents to the question regarding services needed/not getting rated low Services FQOL compared to only 18% ($n=10$) of “no” respondents.

Table 12

Services FQOL by services needed/not getting, collapsed

		Services needed/not getting				Total
		yes	%	no	%	
Services FQOL	low	66	61	10	18	76
	high	43	39	46	82	89
Total		109	100	56	100	165

For the purposes of qualitatively exploring family characteristics of participants who reported high Services FQOL despite reporting challenges in Section A, we looked at the subset of 10 respondents who rated their Services FQOL above 8, despite indicating that there are services they require but are not currently receiving. An examination of the *About Your Family* section revealed that respondents consisted of seven mothers, two fathers and one mother and father team. A table illustrating family characteristics of these respondents can be found in Appendix G. Eight respondents identified their families as being two-parent families. Two respondents (both mothers) identified their families as being one-parent families, one of whom indicated a father who was a caregiver, though he did not live in the home. Half of families indicated siblings living in the home, and some were listed as being caregivers. Two families listed older siblings outside of the home who act as caregivers, and two families listed other relatives outside of the home who act as caregivers. Three families (30% of this subset) indicated having two members with DD, and the other seven families indicated one.

Notably, all families listed several conditions secondary to the primary diagnosis, under ‘other conditions’. Eight families listed behaviour problems as the first ‘other condition’. Nine families reported speech and language problems, six families reported mood/expression/anxiety problems, five reported motor coordination concerns, three cited psychiatric disturbance, and other conditions included asthma, heart problems and seizures. All respondents indicated that family members with DD required support for some, most or almost all aspects of life, and all but one family indicated that members with DD had limitations with regards to communication.

Eight families listed ‘mother’ as the most involved person in the family’s day to day life, and two families listed ‘mother and father’. Five respondents reported personally having more or much more responsibility than they would like for both their family and for family members with DD. The other five respondents indicated that they personally had about the amount of responsibility they would like with regards to their family, and two of these five indicated that they also had about the amount of responsibility they would like with regards to the member with DD. Two others indicated that they had more and much more responsibility than they would like with regards to family members with DD, and one reported having less than the amount of responsibility they would like with regards to family members with DD, commenting that the family member with DD has been in a residence but that the family is still involved in care. Another respondent commented “I am grateful for help from group home”, and two commented on their children requiring a great deal of support to be independent.

FQOL Trends

It is worth noting that, in the Health domain, the proportion of people reporting high Health FQOL was higher overall than those reporting low FQOL. Looking at Table 9, of the

respondents who reported health concerns either with family members with DD or other family members, 84% reported high Health FQOL. Even among families reporting health concerns both with family members with DD and other family members, 58% reported high FQOL. Overall, 74% of respondents reported major health concerns in their family, and only 33% reported low Health FQOL. This trend was evident, though less marked, in the Support from Services domain, where 39% of participants reported high Services FQOL despite there being services they required and were not receiving.

In contrast to Health and Services, a different pattern was seen in the Finances domain, in which few respondents who reported hardship (i.e., below average income, not having basic needs met) reported high Finance FQOL ratings. Rather, in this domain, low Finance FQOL was reported by 37% of participants indicating that all their basic needs were met, by 51% of respondents indicating average income, and even by 13% of participants indicating above average income. Indeed, in our sample of urban Ontarian families, 66% reported average or above average income, 62% reported having all of their basic needs met, and yet only 48% of respondents reported high Finance FQOL.

Study 3

Data Analysis

The third study pertains to the *About Your Family* part of the FQOLS-2006, which asks about family composition. Study 3 comprises two components. First, we investigated differences in domain-level FQOL between one-parent and two-parent families. Second, we investigated group equivalence in domain-level FQOL between families with one vs more than one individual with an intellectual and/or developmental disability.

These family demographics (one-parent vs two-parents, and one vs more than one member with a disability) are likely to be impacted by a country's healthcare system and social services. The aim of our third area of investigation was to determine whether the family demographics in question have a differential impact on FQOL across the nine domains of the FQOLS-2006, among urban families in Ontario. With regards to one-parent vs two-parent families, we evaluated differences between the groups since the literature on the subject, reviewed above, suggests that single parents have additional challenges beyond those faced by two-parent families. With regards to families with one vs more than one member with DD, there is evidence to suggest that FQOL may not be affected by having more than one family member with DD (Patterson et al., 2018). Contrary to their prediction that families with more than one member with DD would report lower FQOL than families with a single member with DD, Patterson et al. found no difference between these groups using the The Beach Center Family Quality of Life Scale, another popular measure of FQOL. For this reason, we employed tests of group equivalence to compare these samples, rather than testing for group differences. We sought to determine whether similar results would be found using the FQOLS-2006.

Overall FQOL for each domain was calculated by summing participants' responses to the Attainment and Satisfaction questions in the B Sections of each domain, as described in study 2, and then averaging them. Thus, in study 3, domain-level FQOL is a score out of 5 – the average of participants' Attainment and Satisfaction scores for a given domain. For the first component of study 3, a mean FQOL score for each domain was calculated for the one-parent families group and for the two-parent families group. These nine mean FQOL scores for each family group were compared to test for statistical differences between the groups. For the second component of study 3, the same procedure was used to generate nine domain-level FQOL scores for each of

the two groups, families with one vs more than one member with a disability. These nine mean FQOL scores for each family group were compared to test for statistical equivalence of the groups.

Results

One-parent vs Two-parent Families

In our sample, 46 respondents reported that their immediate family was a one-parent family and 117 respondents reported that their immediate family was a two-parent family. The responses of the remaining six respondents were excluded because they indicated a family constellation other than one-parent or two-parent families.

Distributions for each group, on each domain, were evaluated for nonnormality. Distributions for five of the nine domains were found to be negatively skewed, for both groups: Health, Family, Values, Careers and Community. Thus, mean scores on these domains were compared using the Mann-Whitney test for two independent samples, a nonparametric test that does not assume a normal distribution, in R. The remaining four domains were normally distributed. The Mann-Whitney test assumes that distributions are the same shape, where the Welch's t test has no such assumption. Thus, when distributions are not identical in shape, the Welch's t test is preferable to the Mann-Whitney test, provided the data are normally distributed. For this reason, mean scores on the Finance, Support from Others, Support from Services and Leisure domains were compared using Welch's independent samples t -tests, in SPSS. The results of the independent samples tests evaluating statistical differences between the two groups across the FQOLS-2006's nine domains are depicted in Table 13.

Table 13

Descriptive Statistics and Independent Samples tests of Domain-Level FQOL by Parent Group

Domain	Group						<i>p</i>	Eta Squared
	One-Parent Families			Two-Parent Families				
	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>		
Health	3.78	0.85	46	3.79	0.78	117	.71	.001
Finance ^a	2.58	0.95	45	3.43	0.95	117	.00*	.140
Family	4.12	0.98	46	4.21	0.79	117	.93	.000
Support from Others ^b	2.96	1.01	46	2.88	0.93	117	.63	.001
Support from Services ^c	3.25	1.08	44	3.31	1.03	117	.76	.001
Values	4.03	0.78	44	4.06	0.78	116	.80	.000
Careers	3.44	0.89	43	3.35	1.13	116	.93	.000
Leisure ^d	3.49	0.86	46	3.59	0.89	116	.53	.002
Community	3.24	0.84	46	3.28	0.89	116	.67	.001

a,b,c,d Welch's *t* tests**p* < .001

Domain-level FQOL of respondents of one-parent and two-parent families differed only in the Finance domain; one-parent families reported significantly lower Financial FQOL than two-parent families. The eta squared value of 0.14 indicates a large effect size, with 14% of the variance in Financial FQOL accounted for by this aspect of family constellation.

One vs More than One Family Member with DD

In our sample, 149 respondents reported having one family member with DD and 20 respondents reported having more than one family member with DD. To tests for group equivalence, we conducted nine two-one-sided *t*-test (TOST) procedures in R, to compare the two groups on domain-level FQOL. The TOST procedure employs the Welch's *t* test, which does not assume equal variances. We set the low and high equivalence bounds at -0.5 and 0.5, respectively, reflecting Cohen's *d* guidelines of the upper bounds of a small effect size. These bounds delineate the smallest effect size of interest (SESOI) – the smallest meaningful effect in

either direction into which our confidence interval must fall for our groups to be considered equivalent. The results of equivalence testing across the nine domains of the FQOLS-2006 are depicted in Table 14.

Table 14

Descriptive Statistics and TOST procedure for Domain-Level FQOL by Family Group

Domain	Group						<i>Equivalence Bounds</i>	<i>90% CI</i>	<i>Cohen's d</i>
	One Member with DD			More than One Member with DD					
	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>			
Health	3.76	0.79	149	3.98	0.80	20	-0.40 and 0.40	-0.54;0.11	-0.27
Finance	3.19	1.00	149	3.03	1.15	19	-0.54 and 0.54	-0.31;0.64	0.15
Family	4.19	0.81	149	4.08	1.03	20	-0.46 and 0.46	-0.30;0.53	0.13
Support from Others	2.90	0.95	149	2.68	0.95	20	-0.47 and 0.47	-0.16;0.61	0.24
Support from Services	3.27	1.03	147	3.50	1.16	20	-0.55 and 0.55	-0.70;0.23	-0.21
Values	4.05	0.78	146	4.03	0.82	20	-0.40 and 0.40	-0.31;0.35*	0.03
Careers	3.41	1.07	145	2.95	1.15	20	-0.56 and 0.56	0.00;0.93	0.42
Leisure	3.54	0.86	148	3.60	0.99	20	-0.47 and 0.47	-0.46;0.34*	-0.07
Community	3.30	0.84	148	3.03	1.06	20	-0.48 and 0.48	-0.14;0.70	0.29

* $p < .05$

Equivalence testing revealed significant results only in the Values and Leisure domains; families with one member with DD and families with more than one member with DD reported equivalent FQOL with regards to their Values and Leisure. The results of the remaining seven TOST procedures were non-significant.

It should be noted that the sample size in the group with more than one family member with DD is small ($n=20$). For this reason, these results should be interpreted with caution. The Cohen's d statistics for all groups indicate small effect sizes. Cohen's d is calculated using the mean difference between groups. Indeed, the mean differences between the groups were very

small, 0.19 on average, on our 5-point FQOL scale. The largest mean difference is found in the Careers domain (0.46) and this is twice that of the next largest mean difference. With a larger sample, the standard error would be lower, thereby decreasing the width of our confidence intervals. It could be that with a larger sample size, particularly in the group with more than one family member with DD, our equivalence tests may yield different results.

The mean for Values and Leisure were extremely close, their mean differences being 0.02 and 0.06, respectively. It is clear that these groups did not differ in terms of FQOL reporting in these domains.

In Study 3, we opted to examine FQOL across the nine domains of the FQOLS-2006 separately, because there is clinical relevance in knowing if being a single parent or having more than one child with DD impacts FQOL in some major life domains and not others. The FQOLS-2006 also yields a Global FQOL score, in the section of the measure asking respondents about their FQOL overall. The Global FQOL score contains two items, Overall Attainment and Overall Satisfaction, rated on 5-point Likert-type scales. Upon comparing groups of families with one vs two parents, and families with one vs more than one member with DD across the nine domains, we sought to examine whether the domain-level FQOL scores used in our calculations were related to Global FQOL in our sample. Correlations between the nine domain-level FQOL subscales containing two items each (domain-level Attainment and Satisfaction), and the Global FQOL scale containing two items (Overall Attainment and Satisfaction), were evaluated using Pearson correlation coefficients (Pearson's r). A correlation matrix is presented in Table 15.

Table 15

Correlation Matrix of FQOLS-2006 Subscales

Subscales	1	2	3	4	5	6	7	8	9	10
1 Health	1									
2 Finances	.241**	1								
3 Family	.331**	.244**	1							
4 Others	.165*	.246**	.138	1						
5 Services	.140	.290**	.148	.344**	1					
6 Values	.277**	.087	.270**	.166*	.073	1				
7 Careers	.242**	.261**	.191*	.221**	.239**	.109	1			
8 Leisure	.357**	.263**	.356**	.283**	.362**	.222**	.190*	1		
9 Community	.234**	.225**	.378**	.333**	.306**	.164*	.252**	.508**	1	
10 Global	.390**	.477**	.300**	.346**	.287**	.229**	.330**	.469**	.382**	1

** $p < .01$, * $p < .05$

Pearson's r values of .10-.30 denote small associations, .30-.50 denote medium associations and .50-1.0 denote large associations. All correlations between domain-level FQOL and Global FQOL were significant at $p=.01$, and the magnitude of the associations ranged from small to moderate ($r = .229-.477$). With regards to associations between domains subscales, most, though not all, were significant, and the range of the correlation coefficients was .073 (between Values and Careers) to .508 (between Leisure and Community).

Discussion

A country's health and social care service systems are likely to impact FQOL among families with members with developmental disabilities (DD), and these can vary widely between countries (e.g., Canada and the U.S.), making evaluation of country-specific properties of FQOL measures salient. The current study aimed to evaluate various aspects of the FQOLS-2006 with a large, uniquely Canadian sample, specifically urban families in Ontario. Study 1 examined the

validity of the factor structure of the FQOLS-2006. Study 2 investigated the relationship between responses to questions in the A and B Sections of domains likely to be influenced by a country's healthcare and social services (Health of the Family, Financial Well-Being and Support from Services). Study 3 compared groups based on family characteristics likely to be influenced by a country's healthcare and social services (one-parent vs two-parent families and one vs more than one family member with DD).

Study 1

With regards to the structural validity of the overall FQOL survey, the data fit the model very well in its first iteration, indicating strong support for the validity of the use of the FQOLS-2006 with urban families in Ontario, excluding the Importance dimension. With regards to the measure's domain-level factor structure, allowing for conceptual overlap between Attainment and Satisfaction, the domains of Health, Family, Values and Community were validly measured by the five indicators (all dimension scores except for Importance). Systematic measurement error was found in the five remaining domains, Finances, Support from Others, Support from Services, Careers and Leisure, and covarying additional error terms in these domains resulted in good model fit. Clinicians must exercise caution when using the FQOLS-2006 with patients, recognizing that there may be conceptual redundancy between the measure's dimensions.

Stability has consistently been found to have a complicated relationship with other variables in the FQOLS-2006. Werner et al. (2009) found that all dimensions co-varied across domains except for Stability. In both Canadian and American CFA studies, Stability was found to be problematic; it had low factor loadings and non-significant pathways across domains (Isaacs et al., 2012; Samuel et al., 2018). In the current study, Stability pathways were

significant in only five of the nine domains, and while it was demonstrated to be a valid factor in the domain models based on their close fit to the data, Stability nevertheless had the weakest relationship with the latent variable across eight of the nine domains.

In examining why Stability may be problematic in factor analysis, it is worth noting the wording of question 5a in Section B of each domain. The question asks participants to estimate the likelihood of a given outcome “In the near future”. This is the only dimension question that is future-oriented, all other dimension questions asking about the family’s current state.

Conceptually, it is difficult to interpret responses to the Stability questions in isolation, since they depend somewhat on responses to other questions. For instance, if a respondent indicates that they are financially well off and have money left over each month after their necessary expenses are paid, a response of 3 on the Stability question, indicating that their situation is likely to “Stay about the same” in the near future, is very different from a 3 response from a participant who has reported struggling financially and not having all of their basic needs met by their income. Even responses of 1 or 5, indicating that their situation will likely “Greatly decline” or “Greatly improve” in the near future, have very different implications for these two families. It is essential to know something about the family’s current state in a given domain to be able to interpret responses to the future-oriented Stability questions. In this sense, the Stability items are not ‘ordered’ in the same way responses to other dimension questions are, where the scales are straightforward and unambiguous (e.g., hardly at all, a little, some, quite a bit, a great deal), and the interpretations need no qualification from responses to other questions. That being said, it makes conceptual sense that the perceived likelihood of improvement or decline in key life domains is a salient factor in FQOL; it comes as no surprise that there is support for this factor in the literature, as it has obvious clinical relevance. Indeed, it is an important consideration in

FQOL, but the fact that its interpretation is not straightforward like the other dimensions of the FQOLS-2006, may pose challenges when trying to formally evaluate it using statistical analyses that specify ordered variables.

The other dimension that was problematic in our CFA was Importance. The majority of respondents reported Importance ratings of 5 (“Very Important”) across all domains, indicating a ceiling effect. This finding is consistent with past Canadian research (Isaacs et al., 2012; Werner et al., 2009). The fact that there was a ceiling effect with regards to Importance ratings among Canadian participants, as well as among a sample of participants from Nigeria, the U.S., and Australia (Isaacs, 2012), is indicative of the etic quality of the FQOLS-2006. Respondents from different countries and cultural backgrounds find all nine domains to be highly important to their FQOL. The same results were also found in studies using samples of Polish families (Ho et al., 2013), and Australian families (Rillotta et al., 2012). Although this means that the Importance dimension is not conducive to statistical analyses that assume normality, it constitutes a type of ‘descriptive’ support for the validity of the nine domains as factors in FQOL. Indeed, it is highly clinically relevant that respondents consistently rate all nine domains as being very important to their FQOL.

Limitations, Future Research and Clinical Considerations

Although CFA is useful for evaluating the validity of a measure’s factor structure, its major limitation is that it does not allow for the investigation of indirect effects of variables, or the complex interactions that may exist between them. Using the CFA model for the Support from Others domain as an example, the finding that Initiative and Satisfaction were correlated raises the question of whether Initiative is related to Satisfaction because it leads first to

Attainment. Are individuals who take initiative more satisfied because they *attain* what they sought? Or do people who take initiative report higher satisfaction ratings regardless of attainment, simply because they have made efforts? Future research could use path modeling to explore these and other interactions between the dimensions and domains of the FQOLS-2006.

Specific to Stability, the dimension question relating to Stability, question 5a of each B Section, asks respondents if their domain-specific situation will greatly improve, improve, stay about the same, decline, or greatly decline in the near future. The question that follows this dimension item, question 5b, asks, “If improve or decline, why?” and participants are given a space to provide a written response. Future research could evaluate responses to this question to glean qualitative information about the Stability dimension. In a clinical setting, evaluation of questions 5a and b could yield important clinical information. For instance, if a respondent reported low scores across other dimensions, and foresaw no change or worse, a decline in their circumstances, this might indicate feelings of hopelessness which could be addressed in intervention. Alternatively, if question 5b were to flag a specific salient event, for example, an older sibling who acts as a caregiver to the family member with DD preparing to leave the home, this is also important information to inform treatment.

Study 2

Past research has focused on dimension questions in Section B of the FQOLS-2006. The current study sought to evaluate the relationship between the more objective general information questions in Section A of the measure, with domain-level FQOL measured by the more abstract Attainment and Satisfaction questions in the B Sections, in the Health, Finances and Services domains. Strong relationships were found whereby respondents reporting challenges in the A

Section questions reported low domain-level FQOL at a higher rate than those who did not report challenges. This is evidence of good convergent validity between items in the measure's A and B Sections.

Notwithstanding, Health FQOL was found to be generally quite high among the urban Ontarian families in our sample, whereby many participants who reported major health concerns in the family also reported high Health FQOL. Other Canadian studies have also found evidence of high Health FQOL (Brown et al., 2006; Werner et al., 2009), though they did not report information about health concerns indicated in Section A. The same finding emerged, though to a lesser degree, in the services domain, where many respondents reported high Services FQOL despite reporting that there were services they required and were not receiving. It could be that these respondents felt well supported by services they *were* receiving, bolstering their Services FQOL, despite also not receiving some services they require. Indeed, a research poster using part of this dataset, looking at barriers to accessing disability-related services, showed that families did access a variety of services for children with DD, although many believed there were also services they needed and were not receiving (Rourke & Perry, 2017).

The opposite pattern emerged in the Finance domain, where a proportion of respondents reporting their basic needs met, and average or above income, nevertheless reported low Finance FQOL. This suggests that families with members with DD may experience financial strain even when their financial circumstances appear to be relatively stable.

Research into Subjective Wellbeing (SWB) has found that, when asked to rate life satisfaction on a single question concerning "life as a whole", Western population samples average 75% of the maximum score on the measurement scale (i.e., 75 out of 100) (Cummins, 2001); SWB has been described as being under 'homeostatic control'. The homeostatic model of

SWB submits that under normal circumstances, there is a very weak relationship between objective external life conditions and life satisfaction (Cummins, 2003), suggesting that people tend to report fairly high (75%) satisfaction regardless of small day-to-day challenges and changes. Facing chronic challenges, however, such as those experienced by caregivers of individuals with DD, can result in homeostatic failure (Cummins & Wooden, 2014). Indeed, caregivers of individuals with DD, on average, have been found to have significantly lower levels of SWB (Brown, MacAdam-Crisp et al., 2006; Cummins, 2001). Individuals in homeostatic failure are highly sensitive to the effects of resources to buffer the challenges they face (Cummins & Wooden, 2014). Our study examines FQOL in domains likely to be affected by the resources available to families. It may be that the health and social services available to families in our sample mitigate some of the challenges they face, protecting FQOL in the specific domains in question. There are, however, potential confounds to the results. These and areas for future research are discussed below.

Qualitative Findings

Although the current study provides evidence of convergent validity between Sections A and B, the fact that the Section A questions do not perfectly predict domain-level FQOL (i.e., some respondents who reported challenges also reported high FQOL and some respondents who did not report challenges reported low FQOL) suggests that Sections A and B each provide unique and important information about respondents. For example, one mother who endorsed major health concerns both with family members with DD and other family members in Section A, also reported that she was a single mother with two children under the age of 18 with DD. She indicated that she had more responsibility than she would like both for the family and the

members with DD, and suggested her children require “constant supervision”. Yet, she reported Health FQOL of 10 in Section B. In cases such as this, where a respondent’s subjective FQOL ratings are seemingly discrepant from their responses to more objective questions about their life circumstances, it is important to investigate further to assess potential causes of the discrepancy. We examined this respondent’s FQOL ratings in other domains to determine whether she had reported high FQOL across all domains. She had not. She reported very high FQOL in the Family, Support from Others, Support from Services, Values, Leisure, and Community domains, however, she did indicate financial and career difficulties. In the Finance domain, she did not respond to the Attainment question, and rated Satisfaction a 3, commenting, “We need more money”. Her Careers FQOL rating was a 5 out of 10 and she commented, “Shortage of jobs for women”. Her Overall FQOL was 6 out of 10, Attainment being a 2, and Satisfaction a 4. Nevertheless, this respondent indicated Health FQOL of 10, suggesting that the healthcare services the family is receiving may offset the health challenges her family is experiencing. In a comment, the respondent indicated “Mother and sons go to regular check ups”. So, while this respondent may experience high Health FQOL, it stands to reason that it may come at a cost to FQOL in other domains (e.g., Finances and Careers), especially for a single parent, being solely responsible for making an income, managing the logistics of getting children to appointments, potentially missing work to do so, etc.

The most notable finding from our qualitative analysis was that respondents reporting high FQOL despite reporting challenges in the domains in question entailed a heterogeneous group. Few patterns emerged when we compared these participants’ responses to *About Your Family* questions and other relevant questions. More noteworthy were some marked differences between respondents who indicated high FQOL despite reporting challenges. Perry’s model of

stress in families of children with DD (2004) makes the distinction between stressors and parental distress; individuals can experience stressors but may, for various reasons, not exhibit distress (e.g., depression, feeling trapped, burnout). Some families may experience homeostatic failure, resulting in diminished levels of life satisfaction, and others may not. Personal and family system characteristics and resources, informal social supports, and formal supports and services interact and can mitigate parental distress (Minnes et al., 2015; Perry, 2004). This may help to explain why members of families with considerable stressors might nevertheless report high FQOL, and why these families might look so different from one another. Still, it is unsurprising that they constitute the minority of the families in our sample.

Not all respondents make use of the opportunity to write qualitative comments, but one participant made particularly thorough use of it, and some of her comments are highlighted here.

She explained:

“Having child with special needs puts a strain on family relationships in every direction/aspect... Having friends and family to talk to is very important; some friends have been lost along the way because they weren't understanding (specifically referring to special needs child)... Don't get out much on own with husband; pass up a lot of opportunities because of lack of child care... Was a [professional for many years] and stopped working after diagnosis (was only supposed to be for a year)... Lack of child care options, demands of home (too much stress)... need more access to services (respite), shorter wait lists... Long wait lists for services (especially funded); private therapy services are expensive... Increased debt, lack of social opportunities (through work). Issues because mother and father have marital stress; positive impact is being able to spend more time with the kids”

These comments capture some of the stressors experienced by families with members with DD. They call attention to the strain placed on marriage and family relationships, the importance of and impact on informal social supports, the importance of formal supports as well as the implications of a lack of them, and the financial and social strain experienced by families, including sacrificing one's career. Indeed, sacrificing one's career has both financial and social

implications since individuals' careers are often a source of social support. Importantly, this respondent also highlighted a positive impact: being able to spend more time with her children. Indeed, she indicated many family leisure activities and reports FQOL of 8 in both the Family and Leisure domains. Interestingly, despite endorsing major medical concerns in the family, the Health domain was the only domain where she reported FQOL of 10. It could be that this is one area where she feels her family is particularly well supported, despite their considerable stressors.

One participant, despite describing his children as having highly complex medical profiles, including heart and bone growth concerns, did not endorse major medical concerns with family members with DD in Section A of the Health domain. This highlights an important consideration in self-report measurement, namely, that individual respondents may define terms and interpret questions differentially. Perhaps the fact that the mother of this family had recently experienced a serious medical condition, in contrast to the longstanding medical concerns of the children, influenced how the father responded to questions about health concerns in the family.

Another definitional consideration specific to the Health domain of the FQOLS-2006, is that what constitutes a "major" health concern depends on respondents' interpretations. For example, where one respondent reports heart problems, another may report a serious skin condition. It would seem that the health concerns of the former are more complex than those of the latter. That conclusion, however, could be misleading; perhaps the health concerns of the former are well managed and those of the latter necessitate more frequent appointments and more hands-on intervention in the home. It is important not to draw broad conclusions based on responses to questionnaire items alone.

One respondent who reported high Finance FQOL despite indicating below average perceived income was a father who listed “mother” as the most involved person in the day to day life of the family member with DD. He also indicated that the family member with DD required support for almost all aspects of life and had limited communication. He reported that he, personally, had about the amount of responsibility he would like for both the family and the individual with DD. This raises the issue of having individuals respond to questions about *family* quality of life. While it may be that the mother of this family would also report having about the amount of responsibility she would like for the family and for the member with DD, she may indicate otherwise. That information is not captured. The father’s high financial FQOL rating suggests that he believes the family is managing financially, despite their income being below average. It would be interesting to know if the family member most involved in the day to day life of the member with DD would respond differently. There could also be a gender bias in responding. All other respondents in this subset (a mother, a daughter and “biological parents”) listed “mother and father” as being most involved in the day to day life of the family member with DD, and indicated that they personally had much more responsibility than they would like for both the family and for the member with DD. Nevertheless, all respondents in the subset reported high FQOL ratings.

There was one notable difference between the two respondents who reported high Finance FQOL despite not having their basic needs met, regarding the various roles and responsibilities of family members. One respondent reported one sibling in the home, not listed as a caregiver, and indicated that she, herself, was the most involved person in the day to day life of the family member with DD. The other respondent indicated that there were two siblings in the home, both listed as caregivers, and he indicated “parents and siblings” as being most

involved in the day to day life of the family member with DD. This evokes an image of one family in which the mother carries the brunt of the responsibility for the family, and another where all family members contribute (though this is likely an oversimplification, and may also speak to differential responding of mothers and fathers). Nevertheless, both respondents reported personally having much more responsibility than they would like both for the family and for the member with DD. Again, this highlights the heterogeneity of respondents in the subsets of our qualitative analyses. It is not apparent from the responses analyzed what might account for the high FQOL ratings reported by these two respondents.

Neither of these respondents was among the previously examined subset of participants reporting high Finance FQOL and below average income. Evaluation of their responses regarding perceived income revealed that both reported having an average total family income. This raises an interesting question as to why their basic needs were reportedly not met. Perhaps some families with members with DD allocate resources to disability-related costs, at the expense of what they view as being more basic financials needs.

One commonality that emerged among the 10 respondents in the Services subset was that family members with DD were reported to have many “other conditions” secondary to their main diagnosis. This might suggest that these are families requiring many different services. It could be that they are attaining, and are satisfied with some services, resulting in high Services FQOL ratings, despite there still being other services they require and are not receiving, consistent with the findings of Rourke & Perry (2017) cited above. Also of note, three families (30% of the Services subset) indicated having two members with DD. This proportion is much higher than that of the overall sample, where only 12% of families reported having more than one child with DD. It stands to reason that more family members with DD could potentially mean more

services needed, thus more potential for both service attainment/satisfaction, as well as services required/not receiving.

Interestingly, of all respondents examined in the Health and Finance subsets, only one responded differentially to the questions asking about 1) amount of personal responsibility for the family and 2) amount of personal responsibility for the family member with DD. This one respondent indicated “more than I would like” to one of the questions, and “much more than I would like” to the other. All other participants in the Health and Finance subsets gave the same response to those two questions, whether it be “about the amount I like”, “more”, or “much more” (of note, no one reported “less” or “much less”). In the Services domain, however, this was not the case. Here, half of respondents indicated that they had about the amount of responsibility they would like for the family, and more responsibility than they would like for the family member with DD. This was a notable difference in responding among the three domains examined. It could be that respondents with family members with DD who have numerous secondary conditions and require a variety of services, some of which they are not receiving, experience an increased sense of responsibility for the family member with DD. Nevertheless, these respondents reported high Services FQOL, suggesting that they are attaining and are satisfied with some services they are receiving.

The heterogeneity of the respondents in the subsets analyzed qualitatively suggests that a complex interaction between a number of factors likely determines respondents' FQOL scores. It is possible that clues as to why these respondents reported high FQOL despite reporting challenges in Section A could be gleaned from their responses to other questions in other dimensions or domains of the FQOLS-2006. Likely though, qualitative information separate

from that captured by the measure would be required to provide a comprehensive profile of a family's unique circumstances.

Limitations, Future Research and Clinical Considerations

One limitation of study 2 is that information was lost when scales were collapsed to perform chi-square analyses. In the Basic Needs section, information was lost by collapsing the “none”, “a few”, “some” and “most” basic needs met groups, though the distinction between all needs met and not all needs met is thought to have real world relevance. Nevertheless, future research might employ other methods, statistical or otherwise, to investigate the differential effects of the various degrees of basic needs not met on FQOL. Likely, interventions would vary based on the severity of a family's need in this area. So too could future research investigate more precise measures of FQOL, collapsing “low”, “medium” and “high” ratings, for example, or even retaining all 5 points on the original scale in the analyses.

Another limitation of this study was that the responses of subsets of participants who reported challenges in Section A and high FQOL in Section B were analyzed in isolation. Only by comparing the responses of these subsets of participants to other groups (e.g., participants who reported challenges and low FQOL), could it be determined whether response patterns were unique to the subset. This would require a large-scale qualitative investigation of the FQOLS-2006 that is beyond the scope of the current project. Furthermore, in light of the finding that the subsets of participants appear to be heterogenous, qualitative interviewing may yield more valuable insights to that end, than would additional qualitative investigation of responses to the survey.

In our dataset of 169 respondents, nine respondents reported that family members with DD did not live in the home, and there is missing data for another 24 respondents who did not respond to the question as to whether or not family members with DD were living in the home, for a total of 33 respondents. Many of these participants reported that family members with DD were over the age of 21, and qualitative comments from many of them suggest that family members with DD may be living in residence or group home settings. In any case, of these 33 participants, 23 identified themselves nevertheless as caregivers to the family members with DD, and nearly all reported that mother and/or father was the most involved family member in the day to day lives of members with DD. Likely some parents remain involved in the lives, and even the care, of family members with DD living outside the home. Nevertheless, the inclusion of these respondents adds some variability to the data. Future research might investigate FQOL ratings among families with members with DD living in the home vs outside of the home, and perhaps among families of young children with DD as opposed to adult offspring with DD. It is likely that families face experiences and challenges unique to various developmental phases and life stages, which would impact FQOL. Indeed, a study in Catalonia found that parents of adults with DD reported higher FQOL ratings than parents of children with DD (Gine et al., 2015). It would be interesting to replicate this study with a Canadian sample.

Whereas the homeostatic model of FQOL pertains only to satisfaction ratings, the current study looks at the sum of Attainment and Satisfaction scores, and “High” FQOL includes scores of 7 or higher. A score of 10 indicates that both Attainment and Satisfaction scores were 5, but a score of 8 could reflect Attainment and Satisfaction scores of 4 and 4, or it could reflect an Attainment score of 5 and a Satisfaction score of 3. We did not examine the relative contributions of Attainment and Satisfaction scores. Furthermore, where the homeostatic model

research focuses on “life as a whole”, the current study focuses on domain-level FQOL. More research is needed to determine whether the theory of homeostatic control applies to domain-level FQOL. To illustrate, both mothers who rated high Health FQOL despite reporting major health concerns both with family members with DD and other family members, gave domain-level Attainment and Satisfaction ratings of 5. It could be that they were ‘satisfied’ because they ‘attained’ in this domain. In the Overall FQOL part of the survey, however, both of these respondents gave overall Attainment ratings of only 2, and yet, rated overall Satisfaction 4, or 75%, consistent with the homeostatic model.

For these reasons, more research would be beneficial to disentangle potential factors contributing to the generally high Health and Services FQOL in our sample. Future research could evaluate domain-level and overall Satisfaction scores separate from Attainment scores, to compare them with the findings of research on homeostatic control. Future research might also compare samples of respondents from different countries with different health care systems and social services, or even samples of respondents living in different provinces and territories within Canada. Finally, volunteer bias may present an additional confound to these results, and it is discussed further in the *general limitations* section below.

There is clinical value in analyzing discrepancies between responses to the more objective questions in the A Sections of the FQOLS-2006, and subjective FQOL ratings in its B Sections. As in the example described above, if a patient were to endorse major concerns in Section A of the survey, and high FQOL in Section B, a clinician would be alerted to potential concerns. It raises questions as to whether an individual is trying to downplay their struggles, is trying to present well, is in denial, or perhaps whether something is working well to mitigate their challenges. Conversely, if FQOL ratings are low, seemingly disproportionate to an

individual's reporting of their circumstances in Section A, a clinician might wonder if a patient is feeling hopeless or depressed. Alternatively, it may be that something else, possibly not captured in the survey, is contributing to the low FQOL rating. Consideration of these factors could help inform treatment in a clinical setting.

Study 3

Little research has been conducted to compare FQOL ratings of one-parent vs two-parent families, and families with one vs more than one member with DD. In study 3, one-parent and two-parent families were found to differ in domain-level FQOL only in the Finance domain, whereby two-parent families reported significantly higher Finance FQOL than one-parent families. This family variable had a large effect on Finance FQOL, accounting for 14% of its variance. Indeed, single parents face additional challenges beyond two-parent families when attempting to simultaneously earn an income and care for family members with DD. It stands to reason that Finance FQOL, consisting of financial Attainment and Satisfaction, would suffer among single parents compared to two-parent families, where two individuals share the task of balancing the financial, practical and emotional demands of the family.

Even considering the relatively small sample of one-parent families ($n=46$), the results reveal very little difference between the groups in the other domains. In the Health and Services domains, for example, the means differ by only 0.01 and 0.06, respectively, on our 5-point scale, indicating a negligible difference in Health and Services FQOL between the groups. The eta square measures too, indicate very little variance in FQOL accounted for by this family variable in the other domains ($<0.2\%$). It could be that some of the additional challenges faced by single-parent families in our sample are mitigated by the health care and social services available to

them, but that they still struggle financially more than two-parent families. There are still logistical matters to navigate to access health care and services, such as transportation and time off work, which may require a great deal of time and money. These results are consistent with the results of study 2, where many people who reported challenges with health and services nevertheless reported high FQOL in those domains, whereas the opposite was true of FQOL ratings in the Finance domain.

With regards to our comparison of families with one vs more than one member with DD, we opted to use tests of equivalence to compare groups, based on the conclusions of an earlier Canadian study that found little effect of this family variable on FQOL. In our sample, we found that families with one member with DD and families with more than one member with DD reported equivalent FQOL ratings in the Values and Leisure domains. Indeed, Cohen's d values indicated negligible effects. We did not find equivalence between the groups on FQOL in the remaining seven domains, despite these also yielding small Cohen's d values.

Limitations and Future Research

The major limitation of study 3, as noted above in the results section, was the small sample size ($n=20$) of the group of respondents who identified having more than one family member with DD. The results of the equivalence analyses must be interpreted with caution. Visual inspection of the means reveals that they are very close together across all domains, except perhaps the Careers domain, where they are still less than one half point apart on our 5-point FQOL scale, and represent a small effect based also on the Cohen's d value. It might be that if our sample were larger, our confidence intervals would be narrower, and our equivalence tests would be significant in other domains as well.

Although we would not conclude from our failed equivalence tests that the groups are different from one another, and less still in light of our small sample size, it is nevertheless worth noting trends in the mean differences. In the Health and Services domains, mean FQOL among families with more than one member with DD was higher than among families with one member with DD. In the other domains, Finance, Family, Support from Others, Careers and Community, mean FQOL was higher among families with only one member with DD than among families with more than one member with DD. More research, with a larger sample of families with more than one member with DD, is needed to elucidate the effect of having more than one family member with DD on domain-level FQOL.

General Limitations

The generalizability of the results in our study is limited because our samples are convenience samples, and are thus not representative of all families who have a member with DD. Indeed, it could be that only families that are functioning relatively well volunteer to participate in research. Families with more pronounced struggles, and parents experiencing higher levels of parental distress, may opt out of participating in research because of the time and energy commitment required. As such, our results may represent an overestimate of FQOL among urban families in Ontario.

Furthermore, the results of the current research may not generalize to the rest of Canada, since health care and many social services are delivered at the provincial and territorial level. Even families who have a member with DD in rural areas of Ontario likely have a different experience from urban families in Toronto, suggesting that the results of the current study likely do not generalize even to all Ontarians.

Conclusions

Beyond the additional financial demands of having family members with DD, the fact that financial issues were highlighted in our sample recruited from Toronto could also point to a broader issue, namely, the increasing affordability crisis in Toronto and the surrounding area (Canadian Rental Housing Index, 2020). In a city where many people spend more than 50 percent of their income on rent (Katawazi, 2019), and home-ownership is prohibitively expensive for many (Kalinowski, 2018), it is perhaps not surprising that financial struggles would emerge in our sample. In Toronto's current economy, balancing a budget on an average income is likely difficult even for families without members with DD.

Also specific to Toronto is the fact that the city is highly multi-cultural and welcomes many newcomers to Canada each year (Statistics Canada, 2017). A study from the UK found markedly higher rates of psychological distress among South-Asian caregivers of individuals with DD (70%) than in the rest of their sample of caregivers of individuals with DD (47% overall) (Emerson et al., 2004). The researchers suggested that that these elevated rates of psychological distress may be mediated by socio-economic deprivation. Newcomer families face a multitude of challenges as they settle into their lives in a new country. Many have pronounced financial difficulties and food insecurity. Some are refugees fleeing war and persecution and have extensive trauma backgrounds. Many have left their family and community support networks behind and have not yet created new networks, and may struggle to do so in the face of language barriers and discrimination. Further, attitudes toward disability, and thus adjustment to having a child with DD, can vary across different cultures. Although the FOQLS-2006 does not ask about country of origin, this question could be included for research

purposes. Research into FQOL among newcomers to Canada would be especially valuable in Toronto where many refugees and immigrants land, and could identify FQOL issues unique to this complex population.

Research into life satisfaction homeostasis has found that having a family member with DD can be a sufficient source of chronic stress as to induce homeostatic failure in some people. Research into stress in families of children with DD has found that some people may be resilient to parental distress and experience positive outcomes. Taken together, and relevant to all three of the current studies, is the notion that conclusions cannot be drawn about individuals based on statistical probabilities. Research is important to validate measures and to increase our understanding of various groups by analyzing patterns among them, but to understand a family's unique set of circumstances, questionnaire responding must be supplemented with qualitative data. Furthermore, FQOL research relies on the reports of individuals to describe family circumstances. This is hugely problematic and calls into question whether measures of FQOL are actually measuring *family* quality of life or *individual* quality of life. An individual's responses to survey questions could be influenced by a multitude of factors including personality, gender, coping skills, attitudes, perceptions and interpretation, and salient idiosyncrasies of individual respondents may not be shared by other family members.

Indeed, research has been conducted to compare responses of mothers and fathers of children with DD across various assessment measures (Olsson & Hwang, 2001; Vilaseca et al., 2014; Wang et al., 2006), revealing similarities and differences in their response patterns. While these studies offer valuable insights, they do not yield qualitative information about mothers' and fathers' unique parenting experiences. Moreover, it may be more difficult to categorize parents based on less concrete individual characteristics than gender (e.g., 'attitudes' or 'coping skills').

Mixed research designs including both quantitative and qualitative elements would allow researchers to access respondents' unique experiences, and would help to clarify confusion created by definitional and interpretation issues. Future research could employ methodology similar to that used by a team of Belgian researchers (Steel et al., 2011), where administration of the FQOLS-2006 was followed by qualitative interviews with respondents.

The same issues must be taken into consideration in a clinical context. Although surveys are an efficient way to gather a lot of valuable clinical information in a relatively short amount of time, they should be used as an adjunct to, not a substitute for clinical interviewing. It is important not to make assumptions or draw broad conclusions based on a single source of information, or even the report of a single respondent, if possible. It is important to supplement questionnaires with clinical interviewing, preferably with multiple family members. The relationships between the domains and dimensions of the FQOLS-2006 are complex, and relationships among family members are highly complex. It is essential to listen to individuals' and families' unique stories and perspectives, to try to understand the complex interaction of factors that determine their quality of life. In this way, interventions can be tailored to meet the unique needs of individuals and families.

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Appendix A

*FQOLS-2006***Family Quality of Life Survey**Main caregivers of people with intellectual or developmental disabilities

2006

Ivan Brown
Roy I. Brown
Nehama T. Baum
Barry J. Isaacs
Ted Myerscough
Shimshon Nelkrug
Dana Roth
Jo Shearer
and Mian Wang

Surrey Place Centre, Toronto, Canada

Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities.

Ivan Brown, Roy I. Brown, Nehama T. Baum, Barry J. Isaacs, Ted Myerscough, Shimshon Neikrug, Dana Roth, Jo Shearer and Mian Wang

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Availability of the Survey Package

The *Family Quality of Life Survey Package* (instructions, an administrator's manual, a codebook for variables, and data files in SPSS and delimited text formats) is currently available in English and may be downloaded free of charge from:
<http://www.surreyplace.on.ca/Education-and-Research/research-and-evaluation/Pages/International-Family-Quality-of-LifeProject.aspx>

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Family Quality of Life Survey

Main Caregivers of People with an Intellectual or Developmental Disability

What Is the Family Quality of Life Survey?

The *Family Quality of Life Survey* (FQOL Survey) is a method of focusing on the quality of life of families who have one or more members with an intellectual or developmental disability. It is a way to address the degree to which family quality of life is enjoyable, meaningful, and supported by the types of resources that are important to family members, as well as the struggles faced by families.

How should the FQOL Survey be used?

The FQOL Survey is intended for two uses. First, it may be useful for service practitioners and family members as part of an overall assessment of support needs and program design. Second, it may be used as an instrument to describe and measure family quality of life, within the limitations of its conceptualization, for research or evaluation purposes.

Structure of the FQOL Survey

There are many ways to look at family quality of life. The FQOL Survey looks at aspects of family life that we consider critical based on previous research and practice.

The FQOL Survey has several parts:

- The first part, *About Your Family*, introduces your family members.
- The following 9 parts address specific areas of family life: health, financial well-being, family relationships, support from others, support from services, influence of values, careers, leisure and recreation, and community integration. Each of these 9 parts has 2 sections. Section A contains questions that gather some general information and provide context. Section B contains questions related to 6 key concepts: importance, opportunities, initiative, attainment, stability, and satisfaction. These questions may seem somewhat repetitive. They are meant to be that way, because they ask the same question about each of the 9 different areas of life.
- The final short part of the FQOL Survey asks for overall impressions of family quality of life.

How Should the FQOL Survey be Administered?

The FQOL Survey may be completed by the main caregiver (self-administration), or completed by a researcher or practitioner with the main caregiver (face-to-face administration). When self-administered, a way should be provided for the main caregivers who have questions to contact someone with knowledge of the survey.

Informed consent should always be obtained in writing from the person responding to the survey.

In some cases, researchers find it useful to augment the information gathered from the survey with a personal interview.

Confidentiality and Ethical Considerations

The completed FQOL Survey contains confidential information. When it is used by service organizations for assessment of support needs and program design, established policies and guidelines followed for all confidential information should be used.

When the FQOL Survey is used for research or evaluation purposes, all personal information of families and individuals with intellectual or developmental disabilities should be concealed, and only aggregate data or anonymous case examples should be reported. Those using this survey should comply with the ethical requirements of their universities, organizations, or relevant governing bodies.

Use of the terms "Intellectual Disability" and "Developmental Disability"

We use the term "Intellectual Disability" in this international survey to denote difficulties with cognitive development or cognitive impairment from a variety of causes because it is the term that is accepted and used internationally. Many countries use other terms that refer to the same condition (e.g., mental retardation in the United States, learning disabilities in the United Kingdom, and developmental disabilities in Canada).

We use the term "Developmental Disability" to denote conditions associated with a wide variety of disabilities that emerge prior to birth or during the developmental (childhood) years. People with developmental disabilities, as the term is used here, may or may not have an intellectual disability.

This survey may be used with people who have either an intellectual disability or developmental disability.

Translation

The Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities was developed in English. It is our wish to translate the survey to other languages, and to make the translated versions available on our website. If you would like to translate the Survey to your language for use in your country, we would be pleased to have you contact us so that we can work together to make it available.

Difficulty downloading the FQOL Survey?

If you encounter difficulty downloading the survey, or obtaining a properly formatted copy, please contact Barry Isaacs: barry.isaacs@surreyplace.on.ca.

Instructions for Completing the FQOL Survey

Who answers the questions in the survey?

The Family Quality of Life Survey is to be completed by the main caregiver of the family member with an intellectual or developmental disability. The main caregiver may be a parent, a sibling, a spouse or life partner, or other family member as defined in the "About Your Family" section (page 1). It is not to be completed by the family member with an intellectual or developmental disability or a family member who may assist in the care, but is not the main caregiver.

When completing this survey

1. Please answer every question as fully as possible.
2. Write in any additional information or comments that might help us to better understand your family's situation in the spaces beside the questions.
3. If a question is not applicable, please say so and explain why.
4. The survey takes about one hour to complete.

For office use only

Participant ID:		
Survey site:		
Date:		
Country:		
Method of Completion:		
☐	Self administered by main caregiver	
☐	Face to face / Telephone administration	
	Interviewer:	
	Occupation:	
	Place of study/work:	
☐	Was there a follow up interview? (check ✓ if yes)	

About Your Family

Around the world people think of families differently. When completing this survey, we ask you to think of your *immediate family* — those people who are closely involved in the day-to-day affairs of your household. Family members may be related by blood or by close personal relationship.

1. What is your relationship to your family member(s) with an intellectual or developmental disability?

(For example: mother, brother, sister, spouse/partner.)

PERSON(S) WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY

2. Please indicate the gender and age for all family members with an intellectual or developmental disability:

(Use the space to the right of the table to add others if needed.)

	Gender	Age	Live at home with you? (check ✓ if yes)
Person 1	☐ Male ☐ Female		
Person 2	☐ Male ☐ Female		
Person 3	☐ Male ☐ Female		

- 3a. Below are some of the specific diagnoses or reasons that may be associated with an intellectual or developmental disability. Please check (✓) any that apply to your family member(s) with an intellectual or developmental disability.

Person 1	Person 2	Person 3	
☐ 1	☐ 1	☐ 1	Intellectual or developmental disability (cause unknown)
☐ 2	☐ 2	☐ 2	Autism Spectrum Disorder
☐ 3	☐ 3	☐ 3	PDD (Pervasive Developmental Disability)
☐ 4	☐ 4	☐ 4	Down syndrome
☐ 5	☐ 5	☐ 5	Prader-Willi syndrome
☐ 6	☐ 6	☐ 6	Fragile X syndrome
☐ 7	☐ 7	☐ 7	Williams syndrome
☐ 8	☐ 8	☐ 8	Rett syndrome
☐ 9	☐ 9	☐ 9	PKU (Phenylketonuria)
☐ 10	☐ 10	☐ 10	Dual diagnosis (intellectual/developmental disability & psychiatric disorder)
☐ 11	☐ 11	☐ 11	Cerebral Palsy
☐ 12	☐ 12	☐ 12	Fetal Alcohol Spectrum Disorder
☐ 13	☐ 13	☐ 13	Other (please specify)
☐ 14	☐ 14	☐ 14	Other (please specify)

- 3b. Often people with an intellectual or developmental disability have other conditions. Please check (✓) any that apply to your family member(s) with an intellectual or developmental disability.

Person 1	Person 2	Person 3	
☐	☐	☐	1 Behavioural problems
☐	☐	☐	2 Mood/expression/anxiety problems
☐	☐	☐	3 Severe psychiatric disturbances (schizophrenia or other psychoses)
☐	☐	☐	4 General problems with motor control/coordination
☐	☐	☐	5 Seizures
☐	☐	☐	6 Alzheimer disease or other types of dementia
☐	☐	☐	7 Major vision impairment
☐	☐	☐	8 Major hearing impairment
☐	☐	☐	9 Sensory integration impairment
☐	☐	☐	10 Speech and/or language difficulties
☐	☐	☐	11 Feeding or eating difficulties (feed tubes, major allergies, sensitivities, etc.)
☐	☐	☐	12 Heart problems
☐	☐	☐	13 Asthma or other respiratory disease
☐	☐	☐	14 Gastro-intestinal/digestive/stomach problems
☐	☐	☐	15 Other (please specify) _____
☐	☐	☐	16 Other (please specify) _____

- 3c. Please describe condition(s) checked in 3b above.

4. What level of disability-related support is needed for your family member(s) with an intellectual or developmental disability?
(Check ✓ one for each family member with an intellectual or developmental disability. Add others if needed.)

Person 1	Person 2	Person 3	
☐	☐	☐	5 Does not require disability-related support
☐	☐	☐	4 Requires disability-related support for only a few aspects of life
☐	☐	☐	3 Requires disability-related support for some aspects of life
☐	☐	☐	2 Requires disability-related support for most, but not all, aspects of life
☐	☐	☐	1 Requires disability-related support for almost all aspects of life

5. What level of communication best describes your family member(s) with an intellectual or developmental disability?
(Check ✓ one for each family member with an intellectual or developmental disability. Add others if needed.)

Person 1	Person 2	Person 3	
☐	☐	☐	5 Able to communicate about a wide variety of topics in a meaningful way
☐	☐	☐	4 Able to communicate within a limited range of topics in a meaningful way
☐	☐	☐	3 Able to communicate needs, wants, and some ideas in a meaningful way
☐	☐	☐	2 Able to communicate basic needs and wants
☐	☐	☐	1 Very little meaningful communication

6. Is there anything else you would like to tell us about your family member(s) with an intellectual or developmental disability?

IMMEDIATE FAMILY

7. Is your immediate family...?

- ☐ 1 a one-parent family
☐ 2 a two-parent family
☐ 3 other (please specify) _____

8. List all of the adults in your immediate family who take a parental role. Please also indicate their ages, whether they live at home with you, and whether they act as caregivers?

<i>Relationship to family member(s) with an intellectual or developmental disability</i>	<i>Age</i>	<i>Live at home with you? (check ✓ if yes)</i>	<i>Act as caregiver? (check ✓ if yes)</i>
Biological Mother			
Step Mother			
Foster Mother			
Biological Father			
Step Father			
Foster Father			
Sibling (specify)			
Other (specify)			
Other (specify)			

9. List the siblings of the person(s) with an intellectual or developmental disability by their relationship. Please specify if adopted, foster, or step-sibling, etc.

<i>Relationship to family member(s) with an intellectual or developmental disability (for example: brother, foster sister, step-brother, adopted sister)</i>	<i>Age</i>	<i>Live at home with you? (check ✓ if yes)</i>	<i>Act as caregiver? (check ✓ if yes)</i>

10. Please list any other people you consider to be members of your immediate family who are not listed above.

<i>Relationship to family member(s) with an intellectual or developmental disability (grandmother, live-in caregiver, etc.)</i>	<i>Age</i>	<i>Live at home with you? (check ✓ if yes)</i>	<i>Act as caregiver? (check ✓ if yes)</i>

11. Which family member(s) is most involved in the day to day life of your family member(s) with an intellectual or developmental disability? (check ✓ one)

- ☐ 1 Mother
☐ 2 Father
☐ 3 Mother and father
☐ 4 Siblings
☐ 5 Parents and siblings
☐ 6 Parents and other family members
☐ 7 Parents, siblings, and other members
☐ 8 Other family members (for example: grandparent, aunt, cousin)

12. How much responsibility do you personally have in the day to day affairs of your family? (check ✓ one)

- ☐ 1 Much more responsibility than I would like
☐ 2 More responsibility than I would like
☐ 3 About the amount of responsibility I like
☐ 4 Less responsibility than I would like
☐ 5 Much less responsibility than I would like

- 13a. How much responsibility related to your family member(s) with an intellectual or developmental disability do you personally have? (check ✓ one)

- ☐ 1 Much more responsibility than I would like
☐ 2 More responsibility than I would like
☐ 3 About the amount of responsibility I like
☐ 4 Less responsibility than I would like
☐ 5 Much less responsibility than I would like

- 13b. Comments:

1. Health of the Family

In this section, you are asked to consider the overall health of your family. Sometimes one or more members of a family have health problems and these problems affect the other members of the family. In responding to the questions below, think of your family as a whole.

Section A

- 1a. Are there major physical and/or mental health concerns for your family member(s) with an intellectual or developmental disability?

- ☐ 1 Yes
☐ 2 No

- 1b. If yes, please describe:

- 2a. Are there any major physical and/or mental health concerns for other members of your family?

- ☐ 1 Yes
☐ 2 No

- 2b. If yes, please describe:

Who? (Relationship to family member(s) with an intellectual or developmental disability)	Health concern

3. What barriers are there to your family accessing health care? (check ✓ as many as apply)

- ☐ 1 Long wait for service
☐ 2 No known treatment for health concern
☐ 3 Services not available in my area
☐ 4 Transportation is a problem
☐ 5 We cannot get to appointments easily, we have trouble getting around
☐ 6 We do not know where to go for health care services
☐ 7 We do not understand easily what health care professionals say
☐ 8 Poor treatment by health care professionals
☐ 9 We have different beliefs about health care
☐ 10 Other (specify) _____
☐ 11 Other (specify) _____

Section B

1. How important is your family's health to your family's quality of life? (check ✓one)

- ☐ 5 Very important
☐ 4 Quite important
☐ 3 Somewhat important
☐ 2 A little important
☐ 1 Hardly important at all

2. Are there opportunities in your area for your family's health needs to be met? (check ✓one)

- ☐ 5 A great many
☐ 4 Many
☐ 3 Some
☐ 2 A few
☐ 1 Hardly any

3. Do members of your family make efforts to maintain or improve their health, such as engaging in regular exercise, paying attention to diet? (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

4. To what degree do members of your family enjoy good health? (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

- 5a. In the near future, is it likely that your family's current level of health will ...? (check ✓one)

- ☐ 5 Greatly improve
☐ 4 Improve
☐ 3 Stay about the same
☐ 2 Decline
☐ 1 Greatly decline

- 5b. If improve or decline, why?

6. All things considered, how satisfied are you with the health of your family?
(check ✓ one)

- ☐ 5 Very satisfied
☐ 4 Satisfied
☐ 3 Neither satisfied or dissatisfied
☐ 2 Dissatisfied
☐ 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.
-
-

2. Financial Well-Being

In this section, you are asked to think about how your family is managing financially. Individual members of your family earn different amounts of money and have different financial needs, but in responding to the questions below, think of the financial situation of your family as whole.

Section A

1. In your country, how would your total family income, including all pensions, be described? (check ✓ one)

- ☐ 5 Well above average
☐ 4 Above average
☐ 3 Average
☐ 2 Below average
☐ 1 Well below average

2. When you think of the total family income, including all pensions, do you consider your family to be (check ✓ one):

- ☐ 5 Well off
☐ 4 Managing well with some extra
☐ 3 Doing okay
☐ 2 Just getting by
☐ 1 Struggling

3. Does your family receive any financial support from sources other than employment (such as gifts, pensions, investment income)? (Please list)

4. What percentage of your total family income, including all pensions, does your family spend each month, on average, for special care, medication, support, or equipment for the family member(s) with an intellectual or developmental disability?

- ☐ 5 None
☐ 4 Less than 10%
☐ 3 10% to 25%
☐ 2 26% to 50%
☐ 1 51% or more

5. How many of your family's basic needs (for example, food, clothing, adequate housing) are met by your family income? (check ✓ one)

- ☐ 5 All
☐ 4 Most
☐ 3 Some
☐ 2 A few
☐ 1 None

- 6a. After all the necessary expenses are paid at the end of each month, does your household have money left to do with as you wish? (check ✓ one)

- ☐ 1 Yes
☐ 2 No

- 6b. If no, does this present a hardship for your family financially? (check ✓ one)

- ☐ 1 Yes
☐ 2 Somewhat
☐ 3 No

Section B

1. How important is financial well-being to your family's quality of life? (check ✓one)

- ☐ 5 Very important
☐ 4 Quite important
☐ 3 Somewhat important
☐ 2 A little important
☐ 1 Hardly important at all

2. Are there opportunities for members of your family to earn enough money to do the things your family wants? (check ✓one)

- ☐ 5 A great many
☐ 4 Many
☐ 3 Some
☐ 2 A few
☐ 1 Hardly any

3. Do members of your family make efforts to maintain or improve the financial situation of your family? (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

4. To what degree does your family's financial situation meet your family's expectations? (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

- 5a. In the near future, is it likely that your family's financial situation will ...? (check ✓one)

- ☐ 5 Greatly improve
☐ 4 Improve
☐ 3 Stay about the same
☐ 2 Decline
☐ 1 Greatly decline

- 5b. If improve or decline, why?

6. All things considered, how satisfied are you with the financial well-being of your family?
(check ☐ one)

- ☐ 5 Very satisfied
☐ 4 Satisfied
☐ 3 Neither satisfied or dissatisfied
☐ 2 Dissatisfied
☐ 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

3. Family Relationships

In this section, think about the general tone or feeling that is usually present in your family. An individual in a family might get along better with some family members than with others, but here we are interested in the atmosphere that emerges from all of the relationships within your family as a whole.

Section A

1. **Who takes responsibility for keeping the day-to-day things going in your family?**
(check ✓ one)

- ☐ 1 Everyone pitches in to the best of their ability
☐ 2 Some do more than others
 Please specify who does more _____
☐ 3 Most responsibility is on one or two people
 Please specify who does most _____
☐ 4 Things just take care of themselves

2. **Who takes the MOST responsibility for each of these nine aspects of running your family home? If responsibilities are shared, list all those involved.** (check ✓ any that apply)

	Mother	Father	Siblings	Other
a. Grocery shopping	☐ 1	☐ 2	☐ 3	☐ 4
b. Cooking	☐ 1	☐ 2	☐ 3	☐ 4
c. Care of person with disability	☐ 1	☐ 2	☐ 3	☐ 4
d. Other child care	☐ 1	☐ 2	☐ 3	☐ 4
e. Yard work	☐ 1	☐ 2	☐ 3	☐ 4
f. House cleaning	☐ 1	☐ 2	☐ 3	☐ 4
g. Laundry	☐ 1	☐ 2	☐ 3	☐ 4
h. Earning money	☐ 1	☐ 2	☐ 3	☐ 4
i. Maintenance and repairs	☐ 1	☐ 2	☐ 3	☐ 4
j. Other (specify) _____	☐ 1	☐ 2	☐ 3	☐ 4
k. Other (specify) _____	☐ 1	☐ 2	☐ 3	☐ 4

3. **To what extent does your family...?** (check ✓ one answer for each item)

	A lot	Quite a bit	Some	Not much
a. Help each other do things	☐ 1	☐ 2	☐ 3	☐ 4
b. Go places together	☐ 1	☐ 2	☐ 3	☐ 4
c. Enjoy each other's company	☐ 1	☐ 2	☐ 3	☐ 4
d. Support each other in times of trouble	☐ 1	☐ 2	☐ 3	☐ 4
e. Help solve family problems	☐ 1	☐ 2	☐ 3	☐ 4
f. Trust each other	☐ 1	☐ 2	☐ 3	☐ 4
g. Work together toward family goals	☐ 1	☐ 2	☐ 3	☐ 4
h. Have a sense of belonging together	☐ 1	☐ 2	☐ 3	☐ 4
i. Generally have similar values	☐ 1	☐ 2	☐ 3	☐ 4
j. Do things as a family	☐ 1	☐ 2	☐ 3	☐ 4

Section B

1. How important are your family relationships to your family's quality of life? (check ✓one)

- ☐ 5 Very important
☐ 4 Quite important
☐ 3 Somewhat important
☐ 2 A little important
☐ 1 Hardly important at all

2. Are there opportunities for members of your family to maintain and enhance good relationships with each other? (check ✓one)

- ☐ 5 A great many
☐ 4 Many
☐ 3 Some
☐ 2 A few
☐ 1 Hardly any

3. Do members of your family make efforts to keep good relationships within your family? (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

4. To what degree do members of your family enjoy good relationships with each other? (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

- 5a. In the near future, is it likely that your family relationships will ...? (check ✓one)

- ☐ 5 Greatly improve
☐ 4 Improve
☐ 3 Stay about the same
☐ 2 Decline
☐ 1 Greatly decline

- 5b. If improve or decline, why?

6. All things considered, how satisfied are you with the relationships within your family?
(check ✓ one)

- ☐ 5 Very satisfied
☐ 4 Satisfied
☐ 3 Neither satisfied or dissatisfied
☐ 2 Dissatisfied
☐ 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.
-
-

4. Support from Other People

Families sometimes get practical and emotional support from a variety of other people, such as relatives, friends, neighbours and others. In this section, you are asked to think about the support to your family as a whole from other people.

Section A

- 1a. How much do relatives (other than those you identified as your immediate family) help your family do *practical* things, such as look after family members, shop, or look after the house? (check ✓one)

- ☐ A great deal
☐ Quite a bit
☐ Some
☐ A little
☐ Hardly at all

- 1b. How many hours a week, in total, do these relatives do these things?

_____ hours

- 2a. How much do relatives (other than those you identified as your immediate family) give your family *emotional* support, such as talk with you, listen to you, or offer encouragement? (check ✓one)

- ☐ A great deal
☐ Quite a bit
☐ Some
☐ A little
☐ Hardly at all

- 2b. How many hours a week, in total, do these relatives do these things?

_____ hours

- 3a. How much do friends and neighbours help your family do *practical* things, such as look after family members, shop, or look after the house? (check ✓one)

- ☐ A great deal
☐ Quite a bit
☐ Some
☐ A little
☐ Hardly at all

- 3b. How many hours a week, in total, do these friends and neighbours do these things?

_____ hours

- 4a. How much do friends and neighbours give your family *emotional* support, such as talk with you, listen to you, or offer encouragement? (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

- 4b. How many hours a week, in total, do these friends and neighbours do these things?

_____ hours

- 5a. How would you describe your own *personal* social life outside your family?
(check ✓one)

- ☐ 3 About what I would like it to be
☐ 2 Somewhat less than I would like it to be
☐ 1 Much less than I would like it to be

- 5b. Please explain:

Section B

1. **How important to your family's quality of life is the practical and emotional support you get from other people, excluding service providers?** (check ✓ one)

☐ 5	Very important
☐ 4	Quite important
☐ 3	Somewhat important
☐ 2	A little important
☐ 1	Hardly important at all

2. **Are there opportunities to receive practical and emotional support from other people, excluding service providers, should your family need it?** (check ✓ one)

☐ 5	A great many
☐ 4	Many
☐ 3	Some
☐ 2	A few
☐ 1	Hardly any

3. **Do members of your family make efforts to get practical and emotional support from other people, excluding service providers?** (check ✓ one)

☐ 5	A great deal
☐ 4	Quite a bit
☐ 3	Some
☐ 2	A little
☐ 1	Hardly at all

4. **To what degree does your family receive practical and emotional support from other people, excluding service providers?** (check ✓ one)

☐ 5	A great deal
☐ 4	Quite a bit
☐ 3	Some
☐ 2	A little
☐ 1	Hardly at all

- 5a. **In the near future, is it likely the practical and emotional support you receive from other people, excluding service providers, will ...?** (check ✓ one)

☐ 5	Greatly improve
☐ 4	Improve
☐ 3	Stay about the same
☐ 2	Decline
☐ 1	Greatly decline

5b. If improve or decline, why?

6. All things considered, how satisfied are you with the practical and emotional support your family gets from other people, excluding service providers? (check ✓one)

- ☐ 5 Very satisfied
- ☐ 4 Satisfied
- ☐ 3 Neither satisfied or dissatisfied
- ☐ 2 Dissatisfied
- ☐ 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

5. Support from Disability Related Services

In this section you are asked to think about the support received from disability related services. Although these services are often directed toward the person with the intellectual or developmental disability, they often affect the family as a whole.

Section A

1. Indicate which of these services, if any, are available in your area. (check ✓ as many as apply)

- ☐ 1 Special disability benefits / funding
- ☐ 2 Service coordination / social work
- ☐ 3 Individual / family support worker
- ☐ 4 Paid attendant or caregiver
- ☐ 5 Respite care
- ☐ 6 In-home health care
- ☐ 7 Advocacy services
- ☐ 8 Special education
- ☐ 9 Supported community employment
- ☐ 10 Sheltered employment workshop
- ☐ 11 Day Programs / Activities
- ☐ 12 Supported group living / group home
- ☐ 13 Supported independent living
- ☐ 14 Institution, residential hospital, or other large care facility
- ☐ 15 Family doctor
- ☐ 16 Pediatrician
- ☐ 17 Medical specialist(s) (please specify) _____
- ☐ 18 Psychiatrist
- ☐ 19 Psychologist
- ☐ 20 Vision services (beyond routine)
- ☐ 21 Hearing services (beyond routine)
- ☐ 22 Nutritional services
- ☐ 23 Speech and language therapy
- ☐ 24 Behavioural support
- ☐ 25 Occupational therapy
- ☐ 26 Physiotherapy
- ☐ 27 Counselling / psychotherapy
- ☐ 28 Other (please specify): _____
- ☐ 29 Other (please specify): _____

2. Which of these services have you or any of your family members used?
(check ✓ as many as apply)

- ☐ 1 Special disability benefits / funding
- ☐ 2 Service coordination / social work
- ☐ 3 Individual / family support worker
- ☐ 4 Paid attendant or caregiver
- ☐ 5 Respite care
- ☐ 6 In-home health care
- ☐ 7 Advocacy services
- ☐ 8 Special education
- ☐ 9 Supported community employment
- ☐ 10 Sheltered employment workshop
- ☐ 11 Day Programs / Activities
- ☐ 12 Supported group living / group home
- ☐ 13 Supported independent living
- ☐ 14 Institution, residential hospital, or other large care facility
- ☐ 15 Family doctor
- ☐ 16 Pediatrician
- ☐ 17 Medical specialist(s) (please specify) _____
- ☐ 18 Psychiatrist
- ☐ 19 Psychologist
- ☐ 20 Vision services (beyond routine)
- ☐ 21 Hearing services (beyond routine)
- ☐ 22 Nutritional services
- ☐ 23 Speech and language therapy
- ☐ 24 Behavioural support
- ☐ 25 Occupational therapy
- ☐ 26 Physiotherapy
- ☐ 27 Counselling / psychotherapy
- ☐ 28 Other (please specify): _____
- ☐ 29 Other (please specify): _____

3a. Are there disability related services you need that you are not currently getting?
(check ✓ one)

- ☐ 1 Yes
- ☐ 2 No

If you answered "No", please move on to Section B on page 22.

If you answered "Yes", continue with questions 3b and 3c on the next page.

3b. If there are disability related services you need that you are not currently getting, please list them.

3c. Why are you not receiving the disability related services you need?
(check ✓ as many as apply)

- ☐ 1 Long wait for service
 - ☐ 2 The services we use just don't help enough
 - ☐ 3 Services not available in my area (please specify) _____
 - ☐ 4 Transportation is a problem
 - ☐ 5 We cannot get to appointments easily, we have trouble getting around
 - ☐ 6 We do not know where to go for services
 - ☐ 7 We do not understand easily what service people say
 - ☐ 8 Poor treatment by staff
 - ☐ 9 We have different beliefs about support services
 - ☐ 10 Other (specify) _____
 - ☐ 11 Other (specify) _____
-

Section B

1. **How important to your family's quality of life is support from Intellectual or developmental disability related services?** (check ✓one)
 - ☐ 5 Very important
 - ☐ 4 Quite important
 - ☐ 3 Somewhat important
 - ☐ 2 A little important
 - ☐ 1 Hardly important at all

2. **Are there opportunities in your area to receive the Intellectual or developmental disability related services your family needs?** (check ✓one)
 - ☐ 5 A great many
 - ☐ 4 Many
 - ☐ 3 Some
 - ☐ 2 A few
 - ☐ 1 Hardly any

3. **Do members of your family make efforts to obtain the disability related services they need?** (check ✓one)
 - ☐ 5 A great deal
 - ☐ 4 Quite a bit
 - ☐ 3 Some
 - ☐ 2 A little
 - ☐ 1 Hardly at all

4. **To what degree are your family's needs, related to the family member(s) with an Intellectual or developmental disability, being met by the services in your area?** (check ✓one)
 - ☐ 5 A great deal
 - ☐ 4 Quite a bit
 - ☐ 3 Some
 - ☐ 2 A little
 - ☐ 1 Hardly at all

- 5a. **In the near future, is it likely that the support your family receives from disability related services will ...?** (check ✓one)
 - ☐ 5 Greatly improve
 - ☐ 4 Improve
 - ☐ 3 Stay about the same
 - ☐ 2 Decline
 - ☐ 1 Greatly decline

5b. If improve or decline, why?

6. All things considered, how satisfied are you with the disability related services your family receives? (check ✓one)

- ☐ 5 Very satisfied
☐ 4 Satisfied
☐ 3 Neither satisfied or dissatisfied
☐ 2 Dissatisfied
☐ 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

6. Influence of Values

Many people derive fulfilment and guidance from the values they hold. Such values may emerge from personal standards of conduct, beliefs based on spirituality, formal religion, or cultural background. For most people, values emerge from a combination of these sources. In this section, you are asked to think about the degree to which your family is influenced by personal, spiritual, religious and cultural values, and to consider their impact on your family as a whole.

Section A

1a. Are your family's values...? (check ✓all that apply)

- ☐ 1 Personal
- ☐ 2 Spiritual
- ☐ 3 Religious
- ☐ 4 Cultural

1b. Please explain: _____

2. To what degree do people in your religious, spiritual/cultural community accept the disability of your family member(s)? (check ✓one)

- ☐ 5 Very much
- ☐ 4 Quite a bit
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Hardly at all
- ☐ 0 Not strongly involved in a spiritual/cultural community

3. To what degree do people in your religious, spiritual/cultural community help your family practically with your disability-related needs? (check ✓one)

- ☐ 5 Very much
- ☐ 4 Quite a bit
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Hardly at all
- ☐ 0 Not strongly involved in a spiritual/cultural community

4. To what degree do people in your religious, spiritual/cultural community help your family emotionally with your disability-related needs? (check ✓ one)

- ☐ 5 Very much
- ☐ 4 Quite a bit
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Hardly at all
- ☐ 0 Not strongly involved in a spiritual/cultural community

5. To what degree do your personal, spiritual, religious and/or cultural values help your family members accept and cope with disability? (check ✓ one)

- ☐ 5 Very much
- ☐ 4 Quite a bit
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Hardly at all
- ☐ 0 Do not have strong personal, spiritual, or cultural values

Section B

1. How important to your family's quality of life are personal, spiritual, religious and/or cultural values? (check ✓one)

- ☐ 5 Very important
☐ 4 Quite important
☐ 3 Somewhat important
☐ 2 A little important
☐ 1 Hardly important at all

2. Are there opportunities for members of your family to develop and hold personal, spiritual, religious and/or cultural values that can contribute to your family's quality of life? (check ✓one)

- ☐ 5 A great many
☐ 4 Many
☐ 3 Some
☐ 2 A few
☐ 1 Hardly any

3. Do members of your family make efforts to maintain or strengthen personal, spiritual, religious and/or cultural values that contribute to your family's quality of life? (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

4. To what degree do members of your family hold personal, spiritual, religious and/or cultural values that contribute to your family's quality of life? (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

- 5a. In the near future, is it likely that the personal, spiritual, religious and/or cultural values that contribute to your family's quality of life will...? (check ✓ one)

- ☐ 5 Greatly improve
☐ 4 Improve
☐ 3 Stay about the same
☐ 2 Decline
☐ 1 Greatly decline

- 5b. If improve or decline, why?

6. All things considered, how satisfied are you with the degree to which personal, spiritual, religious and/or cultural values contribute to your family's quality of life? (check ✓ one)

- ☐ 5 Very satisfied
☐ 4 Satisfied
☐ 3 Neither satisfied or dissatisfied
☐ 2 Dissatisfied
☐ 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

7. Careers and Preparing for Careers

Part of an adult's life is engaging in work. Similarly, part of a child's life is learning for the future. In this section, think of your family as a whole.

Section A

1. List each member of your immediate family by role (for example, mother, step-brother), including the family member(s) with intellectual disabilities, and check (✓) the appropriate occupational activity. Briefly describe the work or school attended.

Family member	Retired	Not employed	Employed Full time	Employed Part time	Student Full time	Student Part time	Describe work or school or why not employed

- 2a. Does your family member(s) with an intellectual or developmental disability engage in the daily activities he/she/they wants?

Person 1	Person 2	Person 3	
☐ 1	☐ 1	☐ 1	Yes
☐ 2	☐ 2	☐ 2	Somewhat
☐ 3	☐ 3	☐ 3	No
☐ 4	☐ 4	☐ 4	Does not apply

- 2b. If no, why not?

- 2c. What daily activities does your family member(s) with an intellectual or developmental disability engage in? (check ✓ all that apply for each family member with an intellectual or developmental disability.)

Person 1 Person 2 Person 3

☐ 1	☐ 1	☐ 1	Community based paid employment
☐ 2	☐ 2	☐ 2	Community based supported employment (paid or unpaid)
☐ 3	☐ 3	☐ 3	Self-employment
☐ 4	☐ 4	☐ 4	Volunteer work
☐ 5	☐ 5	☐ 5	Sheltered workshop
☐ 6	☐ 6	☐ 6	Vocational training
☐ 7	☐ 7	☐ 7	School
☐ 8	☐ 8	☐ 8	Day programs
☐ 9	☐ 9	☐ 9	Other
☐ 10	☐ 10	☐ 10	Does not engage in vocational or educational activities

3. Have any members in your family given up their careers or education to care for the family member(s) with a disability?

- ☐ 1 Yes
☐ 2 No

If you answered "No", please move on to Section B on page 30.
 If you answered "Yes", continue with question 4.

- 4a. Who in your family has given up their career or education to care for the family member(s) with a disability?

- 4b. Please tell us about it:

- 5a. Will they resume in the near future?

- ☐ 1 Yes
☐ 2 Maybe
☐ 3 No

- 5b. Please explain:

6. What impact has this had on your family?

Section B

1. **How important is it to your family's quality of life, for family members to pursue or prepare for the careers they want?** (check ✓one)

- ☐ 5 Very important
☐ 4 Quite important
☐ 3 Somewhat important
☐ 2 A little important
☐ 1 Hardly important at all
☐ 0 Does not apply to my family

2. **Are there opportunities for members of your family to pursue the careers they want and attend the schools they want?** (check ✓one)

- ☐ 5 A great many
☐ 4 Many
☐ 3 Some
☐ 2 A few
☐ 1 Hardly any
☐ 0 Does not apply to my family

3. **Do members of your family make efforts to develop their education and/or careers?** (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all
☐ 0 Does not apply to my family

4. **To what degree have your family members been able to prepare for and have the education and careers they want?** (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all
☐ 0 Does not apply to my family

- 5a. In the near future, is it likely that your family's ability to pursue and prepare for the careers they want will ...? (check ✓one)

- ☐ 5 Greatly improve
☐ 4 Improve
☐ 3 Stay about the same
☐ 2 Decline
☐ 1 Greatly decline
☐ 0 Does not apply to my family

- 5b. If improve or decline, why?

6. All things considered how satisfied are you with your family's careers and ability to prepare for those careers? (check ✓one)

- ☐ 5 Very satisfied
☐ 4 Satisfied
☐ 3 Neither satisfied or dissatisfied
☐ 2 Dissatisfied
☐ 1 Very dissatisfied
☐ 0 Does not apply to my family

7. Please provide any additional information or explanations that you would like.

8. Leisure and Recreation

In this section, consider the leisure and recreation activities of your family as a whole.

Section A

1. What things do members of your family do together in groups of 2 or more people for leisure and recreation?

What 2 or more family members? (for example: mother, father, siblings, person with disability)	Activities they do together

2. What things do members of your family do individually for leisure and recreation?

What family member? (for example: mother, father, siblings, person with disability)	Activities he or she does individually

3. To what degree is your family member(s) with an intellectual or developmental disability involved in your family leisure and recreation activities?

- ☐ 5 Always or almost always
☐ 4 Frequently
☐ 3 Occasionally
☐ 2 Rarely
☐ 1 Not at all

Section B

1. **How important are leisure and recreation to your family's quality of life?** (check ✓one)

- ☐ 5 Very important
☐ 4 Quite important
☐ 3 Somewhat important
☐ 2 A little important
☐ 1 Hardly important at all

2. **Are there opportunities for your family members to engage in leisure and recreation activities?** (check ✓one)

- ☐ 5 A great many
☐ 4 Many
☐ 3 Some
☐ 2 A few
☐ 1 Hardly any

3. **Do members of your family make efforts to take part in leisure and recreation activities?** (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

4. **To what degree do your family members engage in leisure and recreation activities?** (check ✓one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

- 5a. **In the near future, is it likely that your family's leisure and recreation will ...?** (check ✓one)

- ☐ 5 Greatly improve
☐ 4 Improve
☐ 3 Stay about the same
☐ 2 Decline
☐ 1 Greatly decline

- 5b. **If improve or decline, why?**

6. All things considered, how satisfied are you with your family's leisure and recreation?
(check ✓ one)

- ☐ 5 Very satisfied
☐ 4 Satisfied
☐ 3 Neither satisfied or dissatisfied
☐ 2 Dissatisfied
☐ 1 Very dissatisfied

7. Please provide any additional information or explanation that you would like. In particular, please explain if your family members are not able to participate in leisure and recreation activities to the degree they would like.

9. Community Interaction

Community is a sense of connection with people and places in your area. In this section, consider the community interaction of your family as a whole.

Section A

1. What community groups, clubs, or organizations, are members of your family, including the family member(s) with an intellectual or developmental disability, involved in?

Family member	Group, club, or organization

- 2a. Has your family experienced any form of discrimination in your community?

- ☐ 1 Yes
☐ 2 No

- 2b. If yes, please explain

3. What type of community does your family live in? (check ✓ one)

- ☐ 1 Large urban centre
☐ 2 Small city
☐ 3 Small town
☐ 4 Rural
☐ 5 Other (please specify) _____

4. Do you like living in this community?

- ☐ 1 Yes
☐ 2 Somewhat
☐ 3 No

Section B

1. **How important to your family's quality of life is it for members of your family to interact with people and places in your community?** (check ✓ one)

- ☐ 5 Very important
☐ 4 Quite important
☐ 3 Somewhat important
☐ 2 A little important
☐ 1 Hardly important at all

2. **Are there opportunities for members of your family to interact with people and places in your community?** (check ✓ one)

- ☐ 5 A great many
☐ 4 Many
☐ 3 Some
☐ 2 A few
☐ 1 Hardly any

3. **Do members of your family make efforts to interact with people and places in your community?** (check ✓ one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

4. **To what degree does your family interact with people and places in your community?** (check ✓ one)

- ☐ 5 A great deal
☐ 4 Quite a bit
☐ 3 Some
☐ 2 A little
☐ 1 Hardly at all

- 5a. **In the near future, is it likely that your family's interaction with people and places in your community will ... ?** (check ✓ one)

- ☐ 5 Greatly improve
☐ 4 Improve
☐ 3 Stay about the same
☐ 2 Decline
☐ 1 Greatly decline

- 5b. **If improve or decline, why?**

6. All things considered, how satisfied are you with your family's interaction with people and places in your community? (check ✓ one)

- ☐ 5 Very satisfied
☐ 4 Satisfied
☐ 3 Neither satisfied or dissatisfied
☐ 2 Dissatisfied
☐ 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

10. Overall Family Quality of Life

-
1. Are there everyday experiences that *add to* your family quality of life that we have not covered in this survey?

2. Are there everyday experiences that *take away from* your family quality of life that we have not covered in this survey?

3. Is there anything else about your family's structure and/or organization that is important to your family quality of life that we have not asked about in this survey?

4. Is there anything else that is important to your family quality of life that we have not asked about in this survey?

5. Overall, how would you describe your family's quality of life? (check ✓ one)

- ☐ 5 Excellent
☐ 4 Very good
☐ 3 Good
☐ 2 Fair
☐ 1 Poor

6. Overall, how satisfied are you with your family's quality of life? (check ✓ one)

- ☐ 5 Very satisfied
☐ 4 Satisfied
☐ 3 Neither satisfied or dissatisfied
☐ 2 Dissatisfied
☐ 1 Very dissatisfied

7. Finally, what things do you think could improve your family quality of life?

Thank you for completing the Family Quality of Life Survey.

Appendix B

High Health FQOL and Health Concerns – Both

Respondent	Family Characteristics
Respondent 1	relationship: mother single-parent family father listed as caregiver, not in the home children under 18 2 children with DD health concerns - member with DD: 1 child has complex medical profile health concerns - other members: mother, LD and "panic" secondary conditions: behaviour problems, speech/language difficulties, mood/expression/anxiety problems, sensory integration impairment members with DD require support for only a few aspects of life members with DD have some limited ability to communicate most involved person: mother responsibility for member(s) with DD: more than I would like responsibility for family: more than I would like children require constant supervision
Respondent 2	relationship: mother two-parent family 2 grandmothers listed as caregivers, not in the home children under 18 1 child with DD health concerns - member with DD: undiagnosed anxiety health concerns - other members: twin sister, undiagnosed anxiety secondary conditions: behaviour problems, speech/language difficulties, mood/expression/anxiety problems, sensory integration impairment member with DD requires support for some aspects of life member with DD can communicate basic needs and wants, and some ideas most involved person: mother responsibility for member(s) with DD: more than I would like responsibility for family: more than I would like children require constant supervision

Appendix C

High Health FQOL and Health Concerns – Members with DD

Respondent	Family Characteristics
Respondent 1	relationship: mother two-parent family additional caregiver in the home (apart from mother and father) 1 member with DD, between 18 and 29 health concerns - member with DD: psoriasis secondary condition: speech/language difficulties member with DD requires support for most aspects of life member with DD has limited ability to communicate most involved person: mother and father responsibility for member(s) with DD: about the amount I would like responsibility for family: about the amount I would like
Respondent 2	relationship: mother two-parent family additional caregiver in the home (apart from mother and father) 1 member with DD, between 18 and 29 health concerns - member with DD: highly complex medical profile secondary conditions: behaviour problems, speech/language difficulties, mood/expression/anxiety problems, sensory integration impairment, asthma, dementia member with DD requires support almost all aspects of life member with DD can communicate basic needs and wants most involved person: mother responsibility for member(s) with DD: about the amount I would like responsibility for family: about the amount I would like

Appendix D

High Health FQOL and Health Concerns – Other Family Members

Respondent	Family Characteristics
Respondent 1	relationship: father two-parent family children under 18 sister in the home listed as caregiver 2 children with DD and highly complex medical profiles secondary conditions: speech/language difficulties health concerns - other members: mother, recovering from a serious medical condition members with DD require support for "some "and "most" aspects of life members with DD have limited ability for meaningful communication most involved person: mother and father responsibility for member(s) with DD: about the amount I would like responsibility for family: about the amount I would like

Appendix E

High Finance FQOL and Below Average Perceived Income

Respondent	Family Characteristics
Respondent 1	relationship: daughter (the respondent is possibly the parent of a daughter with DD) two-parent family 1 adult member with DD, between 30 and 40 brother and cousin listed as caregivers secondary conditions: behaviour problems, speech/language difficulties, seizures member with DD does not require support member with DD can communicate about a wide variety of topics "people underestimate daughter's ability" most involved person: mother and father responsibility for member(s) with DD: much more than I would like responsibility for family: much more than I would like perceived income: below average
Respondent 2	relationship: mother two-parent family 1 adult member with DD, between 30 and 40 secondary conditions: mood/expression/anxiety problems, seizures member with DD requires support for almost all aspects of life member with DD can communicate basic needs and wants most involved person: mother and father responsibility for member(s) with DD: much more than I would like responsibility for family: more than I would like perceived income: below average
Respondent 3	relationship: father two-parent family 1 adult member with DD, between 30 and 40 secondary conditions: speech/language difficulties, seizures member with DD requires support for almost all aspects of life member with DD can communicate basic needs and wants, and some ideas most involved person: mother responsibility for member(s) with DD: about the amount I would like responsibility for family: about the amount I would like perceived income: below average

Respondent 4 relationship: biological parents
two-parent family
2 children with DD, under 18
secondary conditions: behaviour problems, speech/language difficulties, mood/expression/anxiety problems, seizures
members with DD require support for "some" and "most, but not all" aspects of life
members with DD can communicate basic needs and wants
most involved person: mother and father
responsibility for member(s) with DD: much more than I would like
responsibility for family: much more than I would like
perceived income: well below average

Appendix F

High Finance FQOL and Not All Basic Needs Met

Respondent	Family Characteristics
Respondent 1	relationship: mother two-parent family once child with DD, under 10 one sibling in the home, not listed as a caregiver secondary conditions: speech/language difficulties, behaviour problems, mood/expression/anxiety problems member with DD requires support for almost all aspects of life member with DD has very little meaningful communication most involved person: mother responsibility for member(s) with DD: much more than I would like responsibility for family: much more than I would like basic needs met: some
Respondent 2	relationship: father two-parent family once child with DD, under 10 two siblings in the home, both listed as caregivers secondary conditions: speech/language difficulties member with DD requires support for most, but not all, aspects of life member with DD can communicate basic needs and wants most involved person: parents and siblings responsibility for member(s) with DD: much more than I would like responsibility for family: much more than I would like basic needs met: a few

Appendix G

High Services FQOL and Services Needed/Not Getting

Respondent	Family Characteristics
Respondent 1	relationship: mother two-parent family 1 member with DD between 18 and 29 secondary conditions: behaviour problems, speech/language difficulties, mood/expression/anxiety problems, problems with motor control/coordination, severe psychiatric disturbances member with DD requires support for most, but not all, aspects of life member with DD can communicate within a limited range of topics most involved person: mother responsibility for member(s) with DD: much more than I would like responsibility for family: about the amount I would like
Respondent 2	relationship: mother two-parent family 2 members with DD between 18 and 29 secondary conditions: behaviour problems, speech/language difficulties, mood/expression/anxiety problems members with DD requires support for most, but not all, aspects of life members with DD can communicate about a wide variety of topics most involved person: mother and father responsibility for member(s) with DD: more than I would like responsibility for family: about the amount I would like
Respondent 3	relationship: mother two-parent family 1 child with DD, under 18 secondary conditions: behaviour problems, speech/language difficulties, mood/expression/anxiety problems, severe psychiatric disturbances, asthma, seizures, heart problems member with DD requires support for most, but not all, aspects of life member with DD can communicate basic needs and wants most involved person: mother responsibility for member(s) with DD: more than I would like responsibility for family: much more than I would like

- Respondent 4 relationship: mother
 one-parent family
 1 adult member with DD, between 30 and 40
 secondary conditions: behaviour problems, mood/expression/anxiety problems, problems with motor control/coordination
 member with DD requires support for most, but not all, aspects of life
 member with DD can communicate within a limited range of topics
 most involved person: mother
 responsibility for member(s) with DD: about the amount I would like
 responsibility for family: more than I would like
- Respondent 5 relationship: father
 two-parent family
 1 adult member with DD, between 30 and 40
 secondary conditions: behaviour problems, speech/language difficulties, mood/expression/anxiety problems, severe psychiatric disturbances
 member with DD requires support for most, but not all, aspects of life
 member with DD can communicate basic needs and wants, and some ideas
 most involved person: mother
 responsibility for member(s) with DD: less than I would like
 responsibility for family: about the amount I would like
- Respondent 6 relationship: mother
 two-parent family
 1 child with DD, under 18
 secondary conditions: behaviour problems, speech/language difficulties, problems with motor control/coordination, sensory integration impairment
 member with DD requires support for some aspects of life
 member with DD can communicate basic needs and wants
 most involved person: mother
 responsibility for member(s) with DD: about the amount I would like
 responsibility for family: about the amount I would like
- Respondent 7 relationship: biological mother
 two-parent family
 1 child with DD, under 18
 secondary conditions: speech/language difficulties, problems with motor control/coordination, major hearing impairment, heart problems
 member with DD requires support for some aspects of life
 member with DD can communicate basic needs and wants
 most involved person: mother
 responsibility for member(s) with DD: more than I would like
 responsibility for family: more than I would like

Respondent 8	relationship: biological mother one-parent family father listed as caregiver, not in the home 1 child with DD, under 18 secondary conditions: behaviour problems, speech/language difficulties, problems with motor control/coordination member with DD requires support for almost all aspects of life member with DD can communicate basic needs and wants most involved person: mother responsibility for member(s) with DD: more than I would like responsibility for family: more than I would like
Respondent 9	relationship: mother and father two-parent family 1 child with DD, under 18 secondary conditions: behaviour problems, speech/language difficulties, mood/expression/anxiety problems, problems with motor control/coordination, asthma member with DD requires support for almost all aspects of life member with DD can communicate basic needs and wants most involved person: mother responsibility for member(s) with DD: much more than I would like responsibility for family: more than I would like
Respondent 10	relationship: biological father two-parent family 2 children with DD, under 18 secondary conditions: speech/language difficulties, gastro-intestinal problems, bone growth problems, reflux, heart problems members with DD require support for "some" and "most, but not all" aspects of life members with DD can communicate "within a limited range of topics" and "basic needs and wants, and some ideas" most involved person: mother and father responsibility for member(s) with DD: about the amount I would like responsibility for family: about the amount I would like
