FAMILY QUALITY OF LIFE: MEASUREMENT AND VALIDITY

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Abstract

Raising a child with a developmental disability presents a unique set of challenges for families and these are assumed to affect the family's quality of life (FQOL). The purpose of the current study is to examine convergent and divergent validity of the Family Quality of Life Survey-2006 by comparing it to other family measures, as well as to explore how these measures contribute to overall FQOL. Based on interviews with 30 families of children with developmental disabilities, modest convergent and divergent validity of the FQOL measure was found. A regression revealed that mental health problems and marital satisfaction accounted for most of the variance in overall FQOL. Limitations of the study and directions for future research and improved conceptualization of FQOL are discussed.

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A diagnosis of a developmental disability (DD; sometimes referred to as "mental retardation" or "intellectual disability") is made when a child has an IQ that is below 70 and presents with substantial deficits in adaptive functioning (American Psychiatric Association, 2000). The prevalence of DD in the general population is estimated to be about 1% (Beange, 2002; Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). The cause of DD is unknown in approximately half of the total number of occurrences, but it is often associated with diagnoses such as Down syndrome, fragile X syndrome, cerebral palsy, and Prader-Willi syndrome (McDermott, Durkin, Schupf, & Stein, 2007). Furthermore, a large proportion of individuals with Autistic Disorder are diagnosed with DD (Fombonne, 2003).

Individuals with DD, especially those with additional diagnoses, often present with mental and physical health problems. Common emotional and mental health issues are problems with social interactions, attention, and aggressive behaviour (Dekker, Koot, van der Ende, & Verhulst, 2002). Some potential physical problems include hearing, vision, and motor impairments, as well as seizures (Dykens, 2000). Therefore, raising a child with DD and common comorbid conditions comes with a unique set of challenges for the child's family. In this paper, I will discuss the relative merits of understanding these impacts from a family quality of life perspective and assess the validity of a family quality of life measure.

Factors Relevant to Families' Experience of Raising a Child with DD

Initially, impacts of a child with DD on the family were assumed to be of a negative nature (Summers et al., 2005), but recent literature has shifted to also capture the potentially positive impacts of having a child with DD (Perry, 2004; Samuel, Rillotta, & Brown, 2012). In the context of a DD, factors that may affect families include social support (White & Hastings, 2004), coping styles (Dabrowska & Pisula, 2010), family hardiness (Bower, Chant & Chatwin, 1998), sense of self-efficacy (Paczkowski & Baker, 2007), and additional sources of stress such as financial problems or life events (Perry, 2004; Plant & Sanders, 2007).

Social support from family members, friends, and community members can be a useful resource for families with a child with DD (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Perry, 2004; Trute, 2003; White & Hastings, 2004). Parents of children with DD report less community support than parents of children without DD (Nachshen & Minnes, 2005). Strong networks of social support may be important for a sense of empowerment in parents (Nachshen & Minnes, 2005), self-efficacy (Kersh et al., 2006), and higher levels of well-being (Trute, 2003; White & Hastings, 2004).

Differences in coping styles may also play an important role in the way in which family members deal with having a member with DD. Task-oriented coping consists of taking action to solve problems and is negatively correlated with stress in parents of children with Down syndrome or autism. However, emotion-oriented coping, in which an individual focuses on reducing emotional tension, has been found to be a predictor of stress in these parents (Dabrowska & Pisula, 2010). Coping styles may be determined by personality dispositions that influence the way in which a situation is appraised by an individual (Folkman & Moskowitz, 2004; Glidden, Billings, & Jobe, 2006).

Family hardiness is used to describe the sense of control that the family, as a unit, has over life events (McCubbin, McCubbin, & Thompson, 1986). Family hardiness may not itself be influenced by the presence of a child with a DD (Bower et al., 1998), but it is important to consider this construct because it may contribute to the outcomes of the family. Furthermore, family hardiness is associated with use of effective coping behaviours and higher levels of family functioning (Failla & Jones, 1991).

Bandura (1982) defined self-efficacy as “judgements of how well one can execute courses of action required to deal with prospective situations” (p. 122). Challenging behaviours, such as those often seen in children with DD, may be related to the self-efficacy of parents. The task of raising a child with DD may be perceived as more difficult than that of raising a typically-developing child (Al-Kandari & Al-Qashan, 2010; Jones & Prinz, 2005). High self-efficacy is related to decreased levels of stress, while low self-efficacy is related to depression in parents (Jones & Prinz, 2005).

Finally, there is the much-researched construct of stress, which many researchers agree is experienced to a higher degree by caregivers of children with DD than caregivers of children without DD (Cameron, Armstrong-Stassen, Orr, & Loukas, 1991; Jones, 2004; Plant & Sanders, 2007). While several approaches have been used to conceptualize stress, Perry (2004) proposed a comprehensive model in which stressors are mediated and moderated by a number of variables to result in negative and positive outcomes (see Figure 1). These variables include individual and family resources, such as coping styles, self-efficacy, and family functioning; as well as formal and informal supports, such as family interventions, parent support groups, friends, and family.

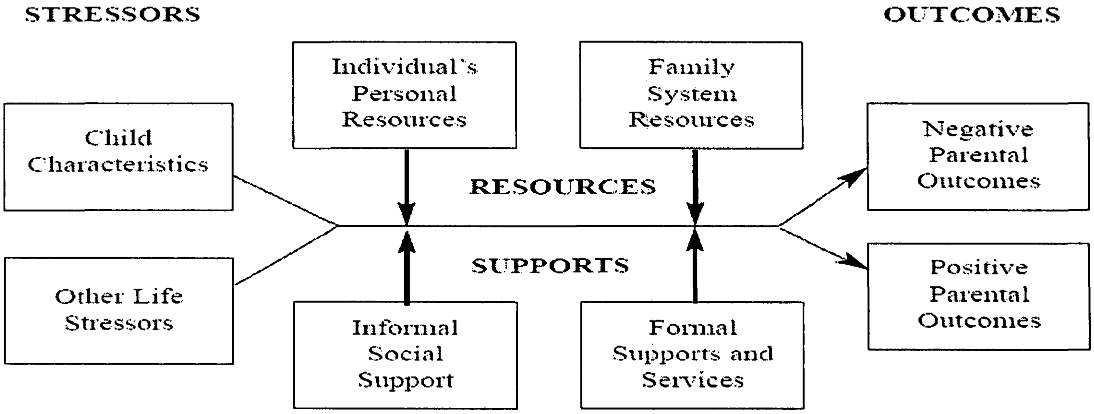


Figure 1. Perry Model of Stress

Family Quality of Life

Family Quality of Life (FQOL) is a relatively new construct that is intended to encompass many aspects of a family's life situation. Conceptualization and measurement of FQOL in the field of DD grew out of extensive work done on the quality of life of individuals with DD, which is briefly reviewed here to provide a context for understanding current approaches to FQOL. Quality of life of individuals with DD has been a highly researched topic, with the assumption that all people deserve to have a high quality of life, including those who have a disability (Brown, 1999; Samuel et al., 2012; Schalock et al., 2002). This construct was explored in order to develop service approaches that are meaningful for individuals with DD and aim to improve their quality of life (Brown, Schalock, & Brown, 2009). In the literature, it has been recognized that an individual's subjective view of his or her quality of life is an important methodological and practical consideration that can guide research, supports, and services (Schalock et al., 2002). Schalock and colleagues (2002) outline five principles that were utilized in the conceptualization of quality of life. These principles are that it is multidimensional, consists of the same factors for all individuals/groups, includes both subjective and objective elements yet is primarily based on the individual's perception, reflects the opportunity an individual has to have his or her wants and needs met, and is based on those individual needs. An area of great debate in the quality of life field has been the balance between objective and subjective measurement, as well as whether quality of life should be examined using specific domains or using a holistic approach that focuses more on capturing the bigger picture (Ager & Hatton, 1998; Cummins, 2001; Cummins, 1997; Hatton, 1998).

Family Quality of Life is a relatively new umbrella construct that aims to capture the different aspects of family life and the level of functioning within those areas (Isaacs et al., 2007; Samuel, Rillotta, & Brown, 2012). Interest in families' quality of life emerged as disability services began to become more focused on families and service providers began to realize the importance of the family unit as a source of support (Poston et al., 2003). Families of children with DD often take on a number of roles in addition to those taken on by families with typically developing children. For example, these families often act as the child's therapist, educators of others, and advocates for services and supports (Turnbull, Poston, Minnes, & Summers, 2007). The five principles that were considered in *individual* quality of life research were influential in the formation of the *family* quality of life construct. Therefore, the five principles applied to FQOL, which mirror those of individual quality of life, are that it is multidimensional, consists of the same dimensions for all individuals/groups, although with different levels of importance perhaps, includes both subjective and objective elements, should be studied using qualitative and quantitative methods, and should be researched to improve the lives of individuals with DD and their families (Isaacs et al., 2007).

Currently, there are two main measures that are used for systematically examining FQOL: the Family Quality of Life Survey-2006 (FQOLS-2006; Brown et al., 2006) and the Beach Center Family Quality of Life Scale (Beach Center FQOL Scale; Beach Center on Disability, 2005). The Beach Center FQOL Scale is a brief self-report measure, which was derived from qualitative research and has had three major modifications since it was first published in 2003 (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). The current version of the Beach Center FQOL Scale contains 25 items that make up five domains: Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-Related Support. Each item is rated for satisfaction using a 5-point scale. Overall, the psychometric properties of this scale support its reliability and validity. The scale is useful when a brief pencil and paper measure is desired.

The FQOLS-2006, which is a revised version of the Family Quality of Life Survey 2000 (Brown, Neikrug, & Brown, 2000), is a very extensive instrument that is typically administered through an in-depth interview. It aims to measure FQOL across nine domains proposed as important areas 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, and Community Interaction. Furthermore, each of the domains is assessed using six dimensions: Importance, Opportunities, Initiative, Attainment, Stability, and Satisfaction. In addition, the last section of the FQOLS-2006 contains two questions assessing overall FQOL using the Attainment and Satisfaction dimensions. There is research showing that Attainment and Satisfaction are most meaningful for the purpose of interpretation of family outcomes (Clark, Brown, & Karrapaya, 2012; Isaacs, Edwards, Baum, & Downie, 2011).

There are a number of unresolved conceptual and measurement issues in the FQOL field, some of which are unique to this new construct but many that were inherited from the approach taken to individual quality of life in DD. A challenge specific to the FQOL construct has been the struggle to distinguish the quality of life of the family as a whole from the quality of life of the reporting family member (Turnbull et al., 2007). Furthermore, there are likely differences between the objective indicators of a family's quality of life and the way in which these families perceive their quality of life. For example, a family may experience health issues but rate themselves as being satisfied with their health. Measures of FQOL should ideally aim to balance objective and subjective elements (Samuel et al., 2012) but it is difficult to distinguish between the two, especially when using a self-report scale. Another debate is whether FQOL can be understood by considering the domains that make up FQOL or whether the whole is greater than the sum of its parts. Current measures of FQOL have mainly adopted the domain approach that examines FQOL in different dimensions. Overall, the FQOL construct continues to be explored and there is still some debate as to its actual meaning and how best to measure it.

In the context of this conceptual confusion, there is also a need for further research on measurement aspects, in particular to support the validity of FQOL measures (Isaacs et al., 2007; Samuel et al., 2012). It is important to ensure that FQOL measures are actually measuring FQOL rather than other constructs often studied in research on families. Caregivers of children with DD have been the focus of research for a number of years and there are many elements that have been examined, such as, social support, stress, coping, and self-efficacy, as noted earlier. Research should aim to establish that FQOL, as it is measured, is different from and more than these individual elements. In other words, the individual domains of FQOL should correlate well with measures that examine similar constructs but an overall score of FQOL should represent something more than just the sum of these constructs.

Research Questions

Research question 1: Convergent and divergent validity of the FQOLS-2006.

To what extent does convergent and divergent validity exist in the FQOLS-2006 domains when it is compared to more traditional family measures? It is hypothesized that portions from the FQOLS-2006 will be strongly correlated with conceptually similar portions of other measures (See Figure 2), while unrelated constructs will show little or no relationship. For example, it is expected that portions that measure the family's health will be highly correlated with each other, but not correlated with portions measuring

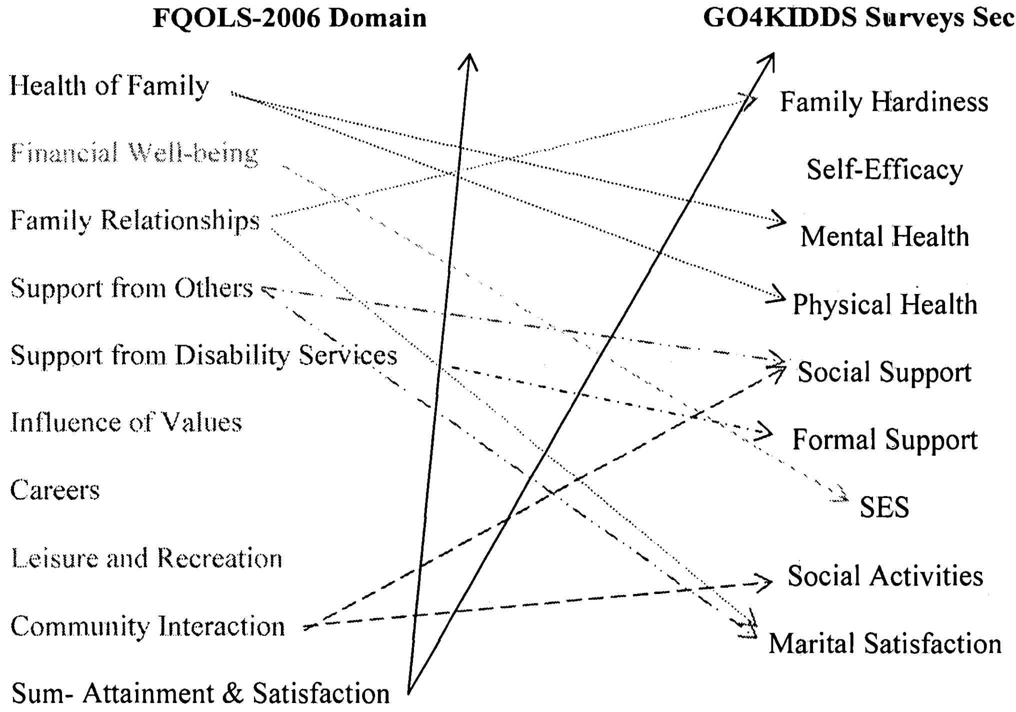


Figure 2. FQOLS-2006 Domains and GO4KIDDS Survey Sections Expected to be Correlated

socioeconomic status. These individual correlations may aid in the distinction between (or assess the degree of overlap between) FQOLS-2006 domains and other variables such as self-efficacy, social support, stress, and coping.

Research question 2: Overall FQOL score in relation to traditional family variables.

How well are overall FQOLS-2006 scores predicted by traditional family variables (e.g., stress, social support, etc.)? It is hypothesized that the different elements will each contribute unique variance, which will provide support for the ability of the FQOLS-2006 to capture a broad variety of factors. Still, it is expected that there will also be a large portion of variance unaccounted for, which will support the notion that FQOLS-2006 captures a unique construct which is greater than the sum of the other constructs.

Method

The data for this study were collected through a larger project called Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS). Through several studies, GO4KIDDS investigates the health, well-being, and social inclusion of school-aged children with severe DD and their families. These particular data came from one component of the GO4KIDDS project that investigates Family Quality of Life (Isaacs & Perry in preparation; Perry & Isaacs, submitted). The collection of data for the FQOL study was approved by the Research Ethics Boards of York University and Surrey Place Centre in Toronto, Ontario.

Recruitment of the primary caregivers was carried out by the researchers (including the author of this thesis) through two methods. The first method involved mailing packages and then phoning caregivers of eligible clients from an agency that provides services to individuals with DD, inviting these caregivers to participate in the FQOL study. The second method involved mailing packages to and then emailing caregivers who had participated in another GO4KIDDS study and indicated interest in participating in future studies. Caregivers who agreed to participate in the FQOL study were assigned to one of six trained interviewers who then made arrangements to meet at a convenient time and place (e.g., family home, coffee shop, service agency). Caregivers gave informed consent by signing one of two forms, depending on whether they were recruited through the agency or through participation in another GO4KIDDS study (See Appendix A for consent forms). The interviews took approximately 1.5 to 2 hours to complete and caregivers were given an honorarium of $50.

Participants

The sample includes 30 ethnically and socioeconomically diverse caregivers of a child with DD. Of the caregivers interviewed, 24 were mothers, three were fathers, and three interviews included both parents together. Caregivers ranged in age from 31 to 57 (*M* = 44.2). See Table 1. The children (20 males, 10 females) ranged from age 6 to 17 years (*M* = 11.67, SD = 3.08). Most of the children have additional diagnoses, including Autism Spectrum Disorder, Down syndrome, Rett syndrome, Fetal Alcohol Spectrum Disorders, cerebral palsy, epilepsy, and Attention Deficit/Hyperactivity Disorder.

Table 1

Caregiver Demographic Information

	N (%) or *M (SD)*
Respondent	
Mother	24 (80)
Father	3 (10)
Both Parents	3 (10)
Family Type	
One-parent	4 (13)
Two-parent	24 (80)
Other	2 (7)
Respondent Age[a]	44.2 (7.02)
Continent of Birth	
North America	20 (67)
Asia	4 (13)
Europe	3 (10)
Missing	3 (10)
Barratt Score (SES)[b]	42.23 (13.62)

[a] $n = 27$; [b] $n = 28$

Measures

Family Quality of Life Survey- 2006.

The FQOLS-2006 (Brown et al., 2006) was used to measure FQOL. Due to the research findings regarding the different dimensions, Attainment and Satisfaction were the only scores that were used since they are the most meaningful for interpreting outcomes. A recent study in this same dataset found excellent internal consistency ($\alpha =$

.85) in a score composed of the sum of these two dimensions (Perry, Isaacs, & O. Weiss, 2012). The Attainment and Satisfaction sums were used as the scores representing each of the nine domains. The sum of the two questions that assess overall FQOL (Section 10 of the measure) were used to represent an Overall FQOL score.

GO4KIDDS Basic and Extended Surveys.

The GO4KIDDS Basic and Extended Surveys (herein referred to as "GO4KIDDS Surveys") were created by the investigators of the GO4KIDDS project (Perry & J. Weiss, 2009). They include items relating to the child, including the diagnostic process, child's physical health, mental health, behaviour, and psychological well-being, service access, school placement, and social inclusion. As well, many items gather information about the caregiver and family, such as the positive and negative impacts of having a child with DD, family stress, satisfaction, parenting efficacy, family hardiness, family satisfaction, marital satisfaction, life events, and social supports. The two surveys look at similar constructs, with the Basic Survey gathering a quick snapshot of the lives of children with DD and their families and the Extended Survey collecting the information in a more comprehensive manner. Both were available online and in paper format. A portion of the items contained in the GO4KIDDS Surveys come from published measures that are valid and reliable and other sections were constructed and internal consistency was calculated for the sample. Those specific GO4KIDDS items and measures included in this study are described below.

Child's adaptive and maladaptive behaviour.

Adaptive and maladaptive behaviour was assessed using the Scales of Independent Behavior- Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996). This well established measure assesses adaptive skills across four domains: Motor, Social Interaction, Communication, and Personal Living, using 35 items each rated on a 4-point Likert scale. In the current sample, this portion of the measure had excellent internal consistency ($\alpha = .93$). Eight forms of maladaptive behaviour (e.g., aggression towards others) are rated based on frequency and severity. This portion of the SIB-R had excellent internal consistency in the current sample ($\alpha = .92$).

Child's diagnosis.

The diagnoses in this study were based on parent report, using a checklist with three (non-mutually exclusive) choices (Developmental Disability, Intellectual Disability, Global Developmental Delay, Developmental Handicap, or Mental Retardation; Autism, Pervasive Developmental Disorder or Autism Spectrum Disorder; Other syndrome or diagnosis- please specify; see Appendix B1). Three of the participants did not complete this portion of the GO4KIDDS Surveys and their responses were gathered using a similar question on the FQOLS-2006. For the current study, diagnoses were categorized into one of three groups: 1) DD only (n=11), 2) ASD only (n=10); or 3) ASD and DD (n=9).

Family hardiness.

Family Hardiness was measured based on items from the Inventory of Family Protective Factors (Gardner, Huber, Steiner, Vazquez, & Savage, 2008; see Appendix

B2). These four items (e.g., “Our family has coped well with one or more major stressors in our lives”) examine the family’s sense of control over their lives using a 5-point Likert scale. The internal consistency of these items was acceptable for such a short scale (α = .78).

Self-efficacy.

Self-efficacy was assessed using the family subscale of the Family Empowerment Scale, sometimes thought to reflect parenting self-efficacy (Koren, DeChillo, & Friesen, 1992; see Appendix B3). Using a 5-point Likert scale, these 12 items encompass the family-level expressions of attitudes, knowledge, and behaviours (e.g., “I believe I can solve problems with my child when they happen”, “I know what to do when problems arise with my child”). This scale had excellent internal consistency (α = .91).

Mental health.

Mental Health was measured using the Kessler-6, which is a short measure consisting of six items, each rated on a 5-point Likert scale, that examine different feelings (e.g., nervousness, hopelessness, sadness; see Appendix B4). A higher score in this section means more negative feelings, i.e., greater psychopathology. This measure was found to be a good screening tool for mental health problems and takes less than two minutes to complete (Kessler et al., 2010). The current study uses a score that represents the average of the six items. In the present sample, the internal consistency of the Kessler-6 was good (α = .86).

Physical health.

We examined Physical Health by asking caregivers to rate their overall physical health on a 5-point Likert scale, ranging from poor to excellent (Appendix B5).

Social support.

Social Support was measured by asking caregivers to rate whether or not they have six potential sources of social support nearby (e.g., parents, friends; see Appendix B6), how often they see them (almost never to every day), and how helpful they are with their child with DD (make it more difficult to extremely helpful). For the present study, the variable used was simply the number of potential sources of social support parents rated as available.

Formal support.

The survey included a list of 20 professionals (e.g., family doctor, social worker, behaviour therapist) providing formal supports and services and caregivers indicated whether their child has ever needed and, if so, ever received each, and parents' level of satisfaction with services from these professionals (if applicable; see Appendix B7). For the analysis in this study, the score that was used represents the mean satisfaction rating of services that the child or family had actually received.

Socioeconomic status.

A score for SES was derived using an adaptation of the Barratt Simplified Measure of Social Status (BSMSS; Barratt, 2006), an updated measure of SES in the Hollingshead tradition. This calculation involved the occupation and highest education level completed of each caregiver (see Appendix B8). This was coded by research assistants and an analysis revealed a high inter-rater reliability ($r = .96$). There is no categorical score but rather a continuous variable. The lowest score that an individual can get on this measure is 8, which is classified by a family in which the parent(s) has/have completed less than 7th grade and may be working as a day laborer, janitor, house cleaner, etc. The highest score possible is 66, which is classified by a family in which the parent(s) has/have completed a graduate degree and may be working as a physician, attorney, professor, etc.

Social activities.

Caregivers were asked to rate the frequency with which they participate in seven different social activities, relative to other people (e.g., having friends over) on a 5-point Likert scale (see Appendix B9). These scores were recoded to better represent "below average" and "above average" ratings of socialization (i.e., "much less than other people" rated as a -2). In this sample, the internal consistency of this portion of the survey was very good ($\alpha = .87$)

Marital satisfaction.

Caregivers who identified themselves as being married or in a long-term relationship were asked how happy their marriage/relationship was, as well as the amount of support that they feel they receive in caring for their child with DD from their partner, each on a 5-point scale (see Appendix B10). The score used consisted of averaging the responses for these two questions, which were strongly correlated ($r = .68, p <.001$).

Results

Preliminary Analyses

Before analysis began, the data were screened and checked in regards to distribution, outliers, and missing data. See Tables 2 and 3 for descriptive statistics on all variables used in subsequent analyses.

Table 2

Descriptive Statistics for the FQOLS-2006

Domain	*M* (SD)	Minimum	Maximum
Health of the Family	7.77 (1.45)	4	10
Financial Well-Being	6.43 (2.01)	2	9
Family Relationships	8.33 (1.65)	3	10
Support from Other People	5.47 (1.92)	2	9
Support from Disability Related Services	6.70 (1.80)	3	10
Influence of Values	8.53 (1.48)	5	10
Careers and Preparing for Careers	5.93 (2.16)	1	9
Leisure and Recreation	7.50 (1.70)	4	10
Community Interaction	6.27 (1.96)	2	10
Overall FQOL Score	6.80 (1.79)	4	10

Table 3

Descriptive Statistics for the GO4KIDDS Surveys

Construct	*M* (SD)	Minimum	Maximum
Child's Adaptive Behaviour[a]	61.55 (19.38)	12	89
Child's Maladaptive Behaviour	-16.27 (11.76)	-43	3
Family Hardiness[b]	3.77 (.64)	2.5	5
Self-efficacy[a]	3.72 (.63)	2.4	5
Mental Health[c]	1.06 (.80)	0	2.7
Physical Health	3.26 (1.02)	1	5
Social Support	3.97 (1.27)	1	6
Formal Support	4.25 (.90)	2.5	5.9
Socioeconomic Status[b]	42.23 (13.62)	9	66
Social Activities[c]	-1.08 (.82)	-2.0	1.6
Marital Satisfaction[c]	3.68 (1.12)	1	5

[a]*n* = 29, [b]*n* = 28, [c] *n* = 27

Then correlations were computed. Since so many correlations were carried out, Type 1 error is an issue if statistical significance is considered. It is more meaningful to look at the strength of the relationship. Cohen (1988) defined correlation strength in the behavioural sciences as being "small" when the correlation is between .10

and .29, "medium" between .30 and .49, and "large" when the correlation coefficient is above .50.

Correlations were performed between the Overall FQOL score and the Attainment and Satisfaction scores of each of the domains: Health of the Family (r = .64), Financial Well-Being (r = .51), Family Relationships (r = .57), Support from Other People (r = .15), Support from Disability Related Services (r = .46), Influence of Values (r = .26), Careers (r = .51), Leisure and Recreation (r = .53), and Community Interaction (r = .74). The Overall FQOL score has a large correlation with most of the domains in the FQOLS-2006, supporting its use as the main outcome measure.

The Overall FQOL score was correlated with a number of child variables: age, adaptive behaviour, and maladaptive behaviour, as well as the family's SES, to check for potential confounds (see Table 4). A Pearson correlation showed a positive relationship between the Overall FQOL score and the child's age (r = .12), the child's adaptive behaviour (r = .25), the child's maladaptive behaviour (r = -.11), and the family's SES (r = .13, p = .50). There was no relationship between the Overall FQOL score and the child's diagnosis ($F_{(2,27)}$ = .08, p =.93). Since none of these relationships appear to be very strong, it was determined that there is no need to control for any of these variables during the subsequent analyses described below. Furthermore, the data were normally distributed, variance was homogeneous, and cases were independent, satisfying the assumptions of parametric data.

Table 4

Correlations between Overall FQOL Score and Stressor Variables

Stressor or Outcome Variable	*r*
Child's Age[a]	.12
Child's Adaptive Behaviour[b]	.25
Child's Maladaptive Behaviour	-.11
Family's SES	.13

[a] $n = 27$, [b] $n = 29$

Convergent and Divergent Validity

The sum of Attainment and Satisfaction scores from each domain were correlated with conceptually similar sections from the GO4KIDDS Surveys, with an expectation of at least modest relationships between hypothetically related constructs. These intercorrelations are shown in Table 5 for all variables. Table 5 shows that there was a strong positive relationship between the FQOLS-2006 Health of the Family domain and the GO4KIDDS Physical Health score ($r = .60$) and a weak negative relationship with Mental Health problems ($r = -.29$). There was a moderate relationship between FQOLS-2006 Financial Well-Being domain and Barratt SES ($r = .34$). As expected, the FQOLS-2006 Family Relationships domain was moderately correlated with Martial Satisfaction ($r = .40$) and Family Hardiness (r=.47). The FQOLS-2006 Support from Other People domain was correlated moderately with Social Support ($r = .38$) and weakly with Marital Satisfaction ($r = .28$). The FQOLS-2006 Support from Disability Services was only weakly correlated with Formal Support (*r* = .28). The FQOLS-2006 Community Interaction domain was weakly correlated with Social Activities (*r* =.25) and Social Support (*r* = .27).

Also shown in Table 5 are a number of correlations which were examined as evidence of divergent validity (i.e., low correlations were expected). In general, these scores were not significantly correlated, although there were some exceptions. The FQOLS-2006 Health of the Family domain had no correlation with Formal Support (*r* = .10). The FQOLS-2006 Financial Well-Being domain had no correlation with Social Support (*r* = -.05), but surprisingly had a moderate correlation with Marital Satisfaction (*r* = .31). The FQOLS-2006 Family Relationships domain had no correlation with Social Support (*r* = .07) or Social Activities (*r* = .06), but had a moderate correlation with Self-Efficacy (*r* = 30). The FQOLS-2006 Support from Other People domain had no correlation with Family Hardiness (*r* = -.08) or Self-Efficacy (*r* = -.08). The FQOLS-2006 Support from Services domain had no correlation with most GO4KIDDS Surveys sections, but interestingly did show a modest correlation with Family Hardiness (*r* = .40) and Marital Satisfaction (*r* = .38). The FQOLS-2006 Influence of Values domain had a weak correlation with Self-Efficacy (*r* = .14), but did have a moderate correlation with Physical Health (*r* = .40). The FQOLS-2006 Careers domain had no correlation with Self-Efficacy (*r* = -.05), but did have a moderate correlation with Mental Health (*r* = -.30), Physical Health (*r* = .35), and Social Activities (*r* = .30). The FQOLS-2006 Leisure and Recreation domain had no correlation

Table 5

Intercorrelations among GO4KIDDS Survey Sections and FQOLS-2006 Domains

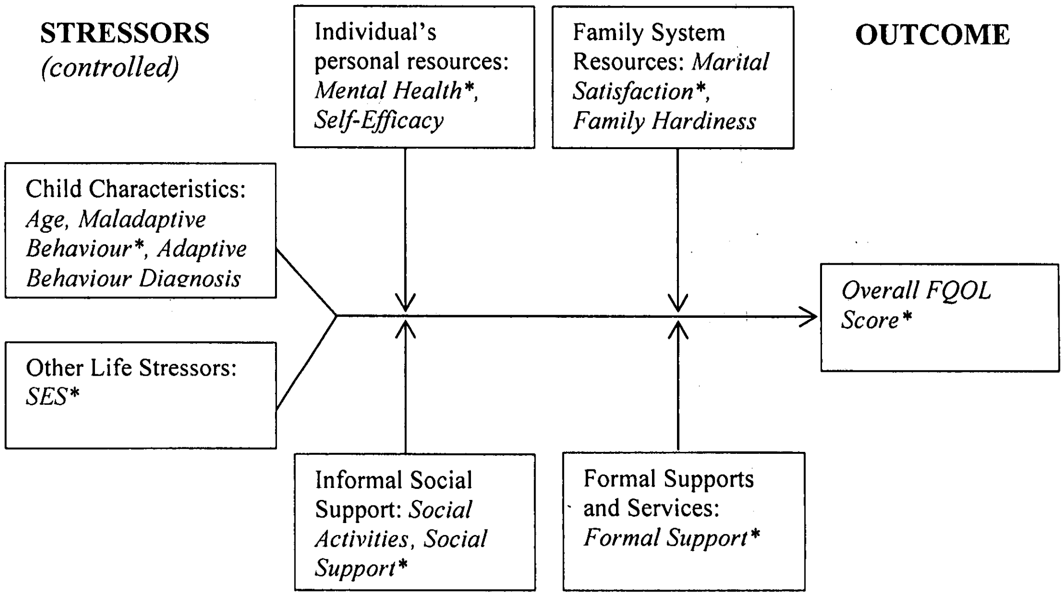
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1. Family Hardiness	1																		
2. Self-Efficacy	.45*	1																	
3. Mental Health	-.23	-.20	1																
4. Physical Health	.10	.20	-.51**	1															
5. Social Support	-.19	-.14	-.21	-.20	1														
6. Formal Support	.33	.31	-.19	.08	,18	1													
7. SES	-.08	.07	.10	.17	.05	.08	1												
8. Social Activities	-.16	-.31	-.49	.37	.36	.26	.18	1											
9. Marital Satisfaction	.50**	.00	-.24	.38	-.02	.16	-.12	.26	1										
FQOLS-2006 Domains																			
10. Health of the Family	.21	.15	-.29	.60**	.14	.10	.14	.14	.23	1									
11. Financial Well-Being	.18	-.19	-.14	.14	-.05	.10	.34	.12	.31	.32	1								
12. Family Relationships	.47**	.30	-.18	.40*	.07	.32	.29	.06	.40*	.55**	.50**	1							
13. Support from Other People	-.08	-.08	-.25	.17	.38*	-.07	.16	.17	.28	.08	.17	.11	1						
14. Support from Services	.40*	.12	-.23	-.13	-.10	.28	-.03	.07	.38	.21	.39*	.13	-.05	1					
15. Influence of Values	.29	.14	-.27	.40*	.21	.22	.18	.18	.18	.60**	.23	.56**	-.01	.13	1				
16. Careers	.11	-.05	-.30	.35	.11	.16	.32	.30	-.12	.46*	.51**	.34	-.04	.20	.14	1			
17. Leisure and Recreation	.07	.01	-.61**	.35	-.11	-.03	-.44	.23	.20	.40*	.39*	.10	.15	.49**	.14	.32	1		
18. Community Interaction	.09	.17	-.36	.42*	.27	-.09	.26	.25	.17	.52**	.56**	.39*	.38*	.40*	.38*	.48**	.52**	1	
19. Overall FQOL	.40*	-.02	-.45*	.51**	.09	.10	.13	.24	.60**	.64**	.51**	.57**	.15	.46**	.26	.51**	.53**	.74**	1

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

with Family Hardiness (*r* = .07) or Self-Efficacy (*r* = .01), but had a strong correlation with Mental Health (*r* = .61) and a moderate correlation with SES (*r* = .44). Finally, the FQOLS-2006 Community Interaction domain had no correlation with Family Hardiness (*r* = .09), but had a moderate correlation with Mental Health (*r* = -.36) and Physical Health (*r* = .42). Overall, with a few exceptions, the FQOLS-2006 appears to have acceptable divergent validity, with conceptually different constructs demonstrating low correlations.

Overall FQOL as Outcome Variable in Perry Model of Stress

A hierarchical multiple regression analysis was performed in order to determine how the family constructs in the GO4KIDDS Surveys contribute to the Overall FQOL score. Due to the small sample size, the number of variables that were used in the hierarchical regression had to be limited. Variables were chosen based on a combination of theoretical and empirical grounds (e.g., relatively normal distribution, good reliability). In order to operationalize the Perry model, stressors, resources, and supports that have been found to be meaningful were included. Figure 3 shows the adjusted Perry Model with the constructs used for the regression indicated. Since previous studies have consistently found that the child's maladaptive behaviour is correlated with outcome variables in caregivers (e.g., Blacher, Neece, & Paczowski, 2005), this was used as the first variable entered into the regression, along with SES, as the "Stressors" (step 1). Next, Mental Health and Marital Satisfaction were entered as the "Resources" (step 2). Finally, Social Support and Formal Support were entered as the "Supports" (step 3). The "Outcome" or dependent variable was the Overall FQOL score.



* Variable used in regression model

Figure 3. Adapted Perry Model of Stress

The results of step 1 demonstrated that Maladaptive Behaviour and SES account for approximately 3% of the variance of the Overall FQOL score, which was not significant ($F_{(2, 25)} = .38, p = .69$). Step 2, during which Mental Health and Marital Satisfaction were added, showed these variables accounted for an additional 43% of the variance, which was a significant amount ($F_{(2, 25)} = 9.89, p = .001$). Finally, when Social Support and Formal Support were added in step 3, the variance accounted for by these variables was less than 1% ($F_{(2, 23)} = .04, p = .96$). In the final model ($F_{(2, 23)} = 3.25, p < .05$), 46% of the variance was accounted for (Adjusted $R^2 = .32$) in Overall FQOL, with significant coefficients for the Mental Health/psychopathology and Marital Satisfaction scores. See Table 6. Thus, although 46% of the variance is noteworthy, 54% of the variance in FQOL was not accounted for by the combination of scores from the GO4KIDDS surveys.

Table 6

Regression Coefficients for GO4KIDDS Survey Sections as Predictors of Global FQOL Score

Step and Predictors	*B*	*SE B*	β
1. Constant	5.86	1.18	
Maladaptive Behaviour	-.02	.03	-.10
SES	.02	.02	.12
2. Constant	3.3	1.5	
Maladaptive Behaviour	-.03	.02	-.18
SES	.02	.02	.14
Mental Health	-.79	.37	-.38*
Marital Satisfaction	.85	.26	.51**
3. Constant	3.82	2.90	
Maladaptive Behaviour	-.03	.02	-.19
SES	.02	.02	.14
Mental Health	-.81	.39	-.34*
Marital Satisfaction	.87	.23	.51**
Social Support	-.03	.26	.02
Formal Support	-.07	.32	-.04

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

Note: $R^2 = .03$ for Step 1, $\Delta R^2 = .43$ for Step 2 ($p < .01$), $\Delta R^2 = .00$ for Step 3, Total $R^2 = .46$ (Adjusted $R^2 = .32$)

Discussion

The purpose of this study was to explore the measurement of the Family Quality of Life construct, as operationalized using the FQOLS-2006 measure. This was done by comparing the FQOLS-2006 to a number of variables from the GO4KIDDS Surveys to investigate convergent and divergent validity. I also examined how the different constructs which were tapped into by the GO4KIDDS Surveys contributed to an Overall FQOL score from the FQOLS-2006.

The domains of the FQOLS-2006 were mostly correlated in sensible ways with the constructs in the GO4KIDDS Surveys. The correlations were quite low, but they may provide some support for the convergent and divergent validity of the FQOLS-2006, demonstrating that the domains of the FQOLS-2006 somewhat measure what they aim to measure, with some limitations as will be outlined below.

The FQOLS-2006 Health of the Family domain appears to be much more correlated with the GO4KIDDS Surveys' Physical Health portion than Mental Health portion, which may indicate that respondents are not considering the mental health of their family as much as physical health while answering this section of the FQOLS-2006. Surprisingly, there was only a small correlation between the FQOLS-2006 Financial Well-Being domain and the GO4KIDDS Surveys' SES portion. Respondents' perceived satisfaction with, and attainment of, financial resources is not matching up with an estimate of their SES based on education and occupation. This may be due to the fact that the SES calculation does not take into account whether or not the family members are currently working. Additionally, factors that impact financial well-being (e.g., medical expenses, other dependents) were not controlled in this study. Another feasible explanation is that respondents' perception of their financial well-being is not necessarily representative of their objective financial standing. FQOLS-2006 Family Relationships was moderately correlated with Family Hardiness on the GO4KIDDS Surveys. Since this section of the FQOLS-2006 is not meant to strictly measure family hardiness, this moderately-sized correlation makes sense. FQOLS-2006 Support from Other People domain and GO4KIDDS Surveys Social Support are only moderately correlated. A possible reason for this is the crude way in which social support was measured (whether or not given supports are nearby), which may not properly represent this construct (various other methods of scoring this measure are also not entirely satisfactory [Ting, Taheri, Perry, & J. Weiss, 2013]). There was only a small correlation between the FQOLS-2006 Support from Disability-Related Services and GO4KIDDS Surveys Formal Support, which may have several explanations. It may reflect the different professionals included in each of the measures. The GO4KIDDS includes generic health care and social services, not just services that are "disability-related". The FQOLS-2006 is meant to be used with individuals across the lifespan, while the GO4KIDDS Surveys target services for children and adolescents. Finally, the FQOLS-2006 Community Interaction domain is only slightly correlated with Social Support and Social Activities. The Community Interaction domain may not be tapping into the conventional social support construct, as there is a focus on community involvement in the form of clubs and organizations. Therefore, it is not surprising that there is not a strong correlation between this domain and the Social Support portion of the GO4KIDDS Surveys.

There were a number of unexpected correlations among some of the domains of the FQOLS-2006 and the GO4KIDDS Surveys. For example, the FQOLS-2006 Family Relationships domain was moderately correlated with Self-efficacy, Formal Support, and Physical Health. Parents who see other family members as more supportive and helpful may also feel more confident in their ability to parent their children effectively. Additionally, family relationships may be stronger when the child's services have been helpful and rated highly, as family members may have more time and motivation to help each other. The FQOLS-2006 Support from Services domain was moderately correlated with Family Hardiness. When a family receives more external support from services, it may increase their sense of control as a family unit because they are able to address the challenges that they are facing. Alternatively, families who are hardier may be more effective at seeking out, and benefiting from, services. FQOLS-2006 Community Interaction was moderately negatively correlated with Mental Health and positively with Physical Health. Families who are actively involved in their community may be less likely to suffer from mental or physical health issues, or the other way around (people with physical and mental health issues less likely to be involved). There is evidence in the literature that a sense of belonging to a community is associated with better mental and physical health (Kitchen, Williams, & Chowhan, 2012).

Next, the contribution of the constructs from the GO4KIDDS Surveys to the Overall FQOL score was examined. It was predicted that the constructs, which are supported in the literature as being meaningful to families, would all contribute a significant portion of the variance. Contrary to this hypothesis, Mental Health and

Marital Satisfaction were the only constructs that contributed significantly. People with higher mental health problems reported a worse quality of life, regardless of other factors related to the child or supports. Since FQOL scores are based on subjective items that are open to interpretation by the respondent, those who report negative emotions (e.g., worthlessness, hopelessness, sadness) may be more likely to rate FQOL dimensions lower. Cummins (2005) points out that individuals are likely to display a pattern of homeostasis, which means they are likely to exhibit similar attitudes in different contexts. In other words, a higher rating of satisfaction with overall life may be the result of a state of positive well-being that permeates other aspects of life, even in difficult circumstances. Conversely, poor mental health may be associated with a lower rating of overall FQOL due to a reflection of actual difficulties, or an overall experience of negative well-being that permeates all aspects of life. Marital Satisfaction also acts as a predictor of the Overall FQOL score, which may be related to the same homeostasis theory. It could also represent the degree to which marriage quality has an effect on perception of the family's overall quality of life, at least in this sample of primarily mothers.

Together, these results suggest that the way in which FQOL was measured for the regression analysis (the Overall FQOL score) is not a cumulative function made up of the constructs that were used in this study. Over half of the variance in Overall FQOL scores was unaccounted for by the current combination of independent variables, suggesting that FQOL is something more or different from the other variables. However, due to this study's sample size (and the limitations that imposes on the number of variables in the regression), it was not possible to include a large number of constructs and important variables that potentially would have accounted for significant variance were not included.

Interestingly, the Overall FQOL score was, at best, weakly correlated with the stressor variables: children's age, adaptive behaviour, maladaptive behaviour, and the family's SES. This is different from other studies, which have found that these variables play a role in other outcome constructs such as parental stress (Plant & Sanders, 2007; J. Weiss, Sullivan, & Diamond, 2003). One explanation is that this sample was made up mostly of children who are in the more severe range. Furthermore, all of the children were still of age to receive particular types and numbers of services and results may have been different if the sample included individuals of a larger age range (e.g., 2-25). Another explanation is that positive outcomes (such as quality of life) in families may not be related to child characteristics in the same way as negative outcomes are (Perry, J. Weiss, & Minnes, 2012). Finally, the FQOL construct is thought to be unique and these child variables may not have the same impact in this area as research shows they have in other family-related constructs.

The results of this study have several implications for the measurement of FQOL. The FQOLS-2006 Attainment and Satisfaction in each domain are only somewhat tapping into similar constructs on other measures. It is not yet clear if the Overall FQOL score provides a valid measure of FQOL. The Overall FQOL score was correlated with all of the domains except for Support from Other People and Values, which is an important finding that demonstrates that nearly all of these domains are contributing to this general score.

When considering a construct such as FQOL, the subjective perception of family members is an important component. The way that an individual feels about his or her quality of life is likely to interact with many aspects of life, such as mental health and sense of self-efficacy. Each of the domains in the FQOLS-2006 contain Section A questions that may provide somewhat more objective information, but these sections were not a focus of this paper. The perception of FQOL may be more meaningful than objective data because it represents the way that the family perceives themselves to be functioning in their current circumstance, regardless of elements that researchers assume contribute to or detract from FQOL.

However, the way in which FQOL is being measured by the FQOLS-2006 may actually represent *individual* quality of life of the parent (in this study, mainly mothers). For example, the large amount of variance in FQOL that mental health and marital satisfaction account for is something that may be unique to mothers and this needs to be explored further. The way in which mental health was measured was specific to the respondent, as was marital satisfaction, which supports the notion that the FQOL score may be most representative of the individual, rather than the family. In order to ensure that *family* quality of life is being measured, it may be necessary to reconsider the way in which the FQOLS-2006 is administered. For example, multiple family members could be involved in providing responses, with a way of integrating different responses and perspectives. Another possibility is to incorporate a standardized procedure that better prompts the respondent to consider the entire family, such as implementing a system of reminders throughout the FQOLS-2006.

There are also a number of clinical implications to consider as a result of this study. The FQOLS-2006 was designed to be used primarily for the purpose of research and evaluation so any clinical utilization should be done in a cautious manner. However, the quality and quantity of information that the FQOLS-2006 gathers is useful for service providers working with families of children with DD. Therefore, it may be worthwhile to consider this if or when this scale is further developed. Since overall family quality of life was best predicted by mental health and marital satisfaction, these may be areas that should be addressed when working with families of children with DD. Finally, the FQOLS-2006 can be used to identify areas of strengths and weaknesses of the family that clinicians can use to determine appropriate services.

This study had a few strengths. It is one of the only studies to compare an FQOL measure to more traditional family measures. This study also examined a unique and complex sample, as all of the families had a child with DD, most of them having multiple co-morbid conditions. The sample was evenly distributed in terms of three child diagnoses. The families' SES was not only greatly variable, but also well distributed, and the sample was quite ethnically diverse. Finally, the amount of information collected from each participant was very extensive and allowed for flexibility in what variables were used for this study.

However, this study also had a number of limitations that should be addressed in future research. First, this sample was quite small and the analyses conducted may have been more meaningful if the sample were larger. In particular, the sample size greatly limited the number of variables that were possible to use in the regression model and more variables were used than recommended for the current sample size, which was thought to be acceptable for an exploratory study and because of the testing of a particular model. This was a purely volunteer sample and may not necessarily be representative of other families with a child with DD (although there was socioeconomic diversity). Because of the sample size and characteristics, the inferences that can made about the general population may be limited.

Another limitation is that the respondents were individuals and, in most cases, the mothers only. It might be useful to conduct this study using the responses of a variety of family members, as mentioned above. Furthermore, the GO4KIDDS Surveys were completed by only one member of the family, with some portions (e.g., Self-efficacy, Mental Health) geared towards the individual, while the FQOLS-2006 aims to capture a picture of the entire family.

There are several measurement issues which limit the study. One possible issue is that the two measures were administered in different ways (interview and self-rating), which may have influenced the results. The variables derived from the GO4KIDDS Surveys may not always have been reliable and valid indicators of the particular constructs involved, especially the social support variable. Finally, the questions on the FQOL rely on the subjective estimate of the respondent, which may not be representative of the FQOL construct. Nevertheless, perceived FQOL may provide unique information about the family's functioning. This is an area of the FQOLS-2006 that is still being explored and it is important to develop a meaningful way of integrating the domain responses.

Future studies should explore the FQOLS-2006 in a larger sample, with other measures, and compare methods of representing FQOL. The GO4KIDDS Family Quality of Life project will be examining some of these factors in a larger sample (Isaacs & Perry, in preparation). It may be interesting and useful to develop a way to incorporate both subjective and objective responses into a comprehensive score and examine the results based on similar methodology as was used in the current study. Family quality of life should also be examined in relation to members' actual or perceived level of optimism, hope, and happiness. These may play a part in determining how a family handles the different challenges associated with raising a child with DD, as well as other challenges in their life (e.g., financial difficulties), which in turn has an effect on their quality of life.

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Appendix A: Information Letter and Informed Consent Forms

g♥4kidds
Great Outcomes for Kids Impacted
by Severe Developmental Disabilities

Online: www.go4kidds.ca
Phone: (416) 736-5662
Toll free: 1-877-233-4337
Fax: (416) 736-5814
Email: go4kidds@yorku.ca

Information Letter for Parents

> *You are invited to participate in an exciting new research project about family quality of life with school-age children with severe developmental disabilities.*

Title: Investigating the Quality of Life in Parents of Children with Severe DD as Compared to Parents of Children with Mild DD

You have received this letter as a parent who has completed our Basic and Extended Surveys and have expressed interest in participating in future studies.

What is this project about?
This study explores your family quality of life (FQOL) with a developmentally disabled child. FQOL is related to both family and community factors that are essential for the health and well-being of children. This includes things like finances, careers, family health, social supports, values, and relationships. Our major goals are to:

- Profile families with children with severe DD.
- Describe how their life experiences differ from those of families who have a child with mild DD.
- Use this information to improve service delivery to better meet the needs of both the family and the child.

What will we ask you to do?
One of our researchers will contact you to arrange a meeting at your convenience. We will then conduct a one-on-one interview with you which focuses on family quality of life.

How long will it take?
Your participation in this study will take about 1 ½ hours. You will receive a $50 honorarium for your time upon the completion of the FQOL interview.

How will your information be used?

- All information we collect from families is private and kept confidential. No one will see the answers you give to questions except members of the research team. Each participant will be given an ID number. Whenever information is put in the computer only the ID number is used, there will be no names attached.

- All information will be stored in a locked filing cabinet or secured on a password-protected computer.

- Your name or your child's name will not be in any reports or publications and no one will know your answers to our questions.

- Your participation in this study is completely voluntary and you may withdraw at any time, without penalty. You do not have to answer all questions if you don't want to.

- If you decide not to answer some questions or decide not to participate in the study at all, the support you and/or your child receive from agencies and professionals involved in the study will not change.

How can you become part of this family quality of life project?

- To participate in our study, **please fill out the consent form** on the next page. Send one copy back to us in the enclosed stamped envelope and keep a copy of this information sheet for yourself.

For more information about this project, please contact:

Tiffany Guanlao, Research Coordinator
416-736-5662, tguanlao@yorku.ca

Adrienne Perry, PhD. Principal Investigator, Department of Psychology, York University
416-736-5115 x33765 perry@yorku.ca

Dr. Alvin Loh., at Surrey Place Centre
416-925-5141 x2335 alvin.loh@surreyplace.on.ca

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FQOL Consent Form

All my questions about this project have been answered and I understand that:

- My participation is completely voluntary and I may withdraw from the project at any time.
- I do not have to answer all of the questions.
- If I do not answer some of the questions or withdraw from the project, it will have no impact whatsoever on my child or family receiving service from the researchers, York University or any organization or group associated with this project in the future.
- All information will be kept confidential, to the fullest extent possible by law (the law requires that confidentiality must be broken if situations arise that put anyone at risk of harm).
- Reports about the project's findings will not include my name or the name of my child.
- In the event that I withdraw from the study, all associated data collected will be immediately destroyed.
- There are no particular risks if I participate although I may feel some discomfort talking about my child's development and the challenges I have faced in gaining access to services. If this does occur, I understand I may refer to the project website for a list of supportive resources and/or may contact project staff at the toll free number given above.
- I may keep a copy of this consent form for my records.

If I have any questions or concerns about this project, I may contact:

Tiffany Guanlao, Research Coordinator, 416-736-5662

Adrienne Perry, PhD., Principal Investigator, at any time at 416-736-5115 x33765.

Barry Isaacs, PhD., Surrey Place Centre, any time at 416-925-5141 x2250.

If my concerns are not answered, I may contact:

Maire Percy, Co-Chair Research Ethics Board, Surrey Place Centre, at 416-925-5141 x2353.

Alison Collins-Mrakas, Senior Manager & Policy Advisor, Research Ethics, York University, 416-736-5914

I understand that by signing this consent form, I am agreeing to participate in this project.

______________________________ ______________________
Print name Date

____
Signature of parent or caregiver

I can be reached by phone: ________________ or **by e-mail:** ________________

The best time of day or week to reach me is: ______________________________

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FQOL Consent Form

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- I do not have to answer all of the questions.
- If I do not answer some of the questions or withdraw from the project, it will have no impact whatsoever on my child or family receiving service from the researchers, York University or any organization or group associated with this project in the future.
- All information will be kept confidential, to the fullest extent possible by law (the law requires that confidentiality must be broken if situations arise that put anyone at risk of harm).
- Reports about the project's findings will not include my name or the name of my child.
- In the event that I withdraw from the study, all associated data collected will be immediately destroyed.
- There are no particular risks if I participate although I may feel some discomfort talking about my child's development and the challenges I have faced in gaining access to services. If this does occur, I understand I may refer to the project website for a list of supportive resources and/or may contact project staff at the toll free number given above.
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If my concerns are not answered, I may contact:

Alison Collins-Mrakas, Senior Manager & Policy Advisor, Research Ethics, York University, 416-736-5914

I understand that by signing this consent form, I am agreeing to participate in this project.

Print name ______________________________ Date ____________________

Signature of parent or caregiver ______________________________

I can be reached by phone: ____________________ or **by e-mail:** ____________________

The best time of day or week to reach me is: ____

Appendix B: GO4KIDDS Basic and Extended Survey Portions

B1. Diagnosis

1.A3. Which one of the following best describes your child's diagnosis? *(check all that apply)*

- ☐ Developmental Disability, Intellectual Disability, Global Developmental Delay, Developmental Handicap, or Mental Retardation
- ☐ Autism, Pervasive Developmental Disorder (PDD) or Autism Spectrum Disorder (ASD)

Other syndrome or diagnosis (please specify______________________________)

B2. Family Hardiness

I3. Family Hardiness - How true are the following statements for your family?

	Not True At All	*Mostly Not True*	*Somewhat True*	*Mostly True*	*Very True*
1. Our family has been able to resolve many (but not all) of our problems by ourselves.	*1*	*2*	*3*	*4*	*5*
2. Our family has control over many (but not all) events in our lives.	*1*	*2*	*3*	*4*	*5*
3. Our family has coped well with one or more major stressors in our lives.	*1*	*2*	*3*	*4*	*5*
4. Our family has been able to "make the best out of a bad situation" a number of times.	*1*	*2*	*3*	*4*	*5*

B3. Self-Efficacy

I2. Parenting Efficacy - Below are a number of statements that describe how a parent or caregiver may feel about his or her situation. For each statement, please circle the response that best describes how the statement applies to you.

	Not True At All	*Mostly Not True*	*Somewhat True*	*Mostly True*	*Very True*

1. When problems arise with my child, I handle them very well.	*1*	*2*	*3*	*4*	*5*
2. I feel confident in my ability to help my child grow and develop.	*1*	*2*	*3*	*4*	*5*
3. I know what to do when problems arise with my child.	*1*	*2*	*3*	*4*	*5*
4. I feel my family life is under control.	*1*	*2*	*3*	*4*	*5*
5. I am able to get information to help me better understand my child.	*1*	*2*	*3*	*4*	*5*
6. I believe I can solve problems with my child when they happen.	*1*	*2*	*3*	*4*	*5*
7. When I need help with problems in my family, I am able to ask for help from others.	*1*	*2*	*3*	*4*	*5*
8. I make efforts to learn new ways to help my child grow and develop.	*1*	*2*	*3*	*4*	*5*
9. When dealing with my child, I focus on the good things as well as the problem.	*1*	*2*	*3*	*4*	*5*
10. When faced with a problem involving my child, I decide what to do and then do it.	*1*	*2*	*3*	*4*	*5*
11. I have a good understanding of my child's needs.	*1*	*2*	*3*	*4*	*5*
12. I feel I am a good parent.	*1*	*2*	*3*	*4*	*5*

B4. Mental Health

1.C3. Feelings - During the **past 4 weeks** how much of the time did you feel…					
	None of the time	*A little of the time*	*Some of the time*	*Most of the time*	*All of the time*
1. So sad nothing could cheer you up	*0*	*1*	*2*	*3*	*4*
2. Nervous	*0*	*1*	*2*	*3*	*4*
3. Restless or fidgety	*0*	*1*	*2*	*3*	*4*
4. Hopeless	*0*	*1*	*2*	*3*	*4*
5. That everything was an effort	*0*	*1*	*2*	*3*	*4*
6. Worthless	*0*	*1*	*2*	*3*	*4*

B5. Physical Health

1.C4. Overall, how is your physical health?

1. Poor
2. Fair
3. Mixed
4. Good
5. Excellent

B6. Social Support

I8. Social Support - For the following chart, please indicate whether you have each type of person nearby, how often you see them, and how helpful/supportive they are with your child with developmental/intellectual disabilities.

	Have near?	How often you see them?	How helpful/supportive with child?
1. Your parents	*Yes* *No*	1 Almost never 2 Once a month or less 3 Between once a month and once a week 4 About once a week 5 Every day	1 Make it more difficult 2 Not helpful 3 Somewhat or sometimes helpful 4 Very helpful 5 Extremely helpful, I depend on them
2. Your in-laws	*Yes* *No*	1 Almost never 2 Once a month or less 3 Between once a month and once a week 4 About once a week 5 Every day	1 Make it more difficult 2 Not helpful 3 Somewhat or sometimes helpful 4 Very helpful 5 Extremely helpful, I depend on them
3. Other extended family	*Yes* *No*	1 Almost never 2 Once a month or less 3 Between once a month and once a week 4 About once a week 5 Every day	1 Make it more difficult 2 Not helpful 3 Somewhat or sometimes helpful 4 Very helpful 5 Extremely helpful, I depend on them

4. Friends	*Yes No*	1 Almost never 2 Once a month or less 3 Between once a month and once a week 4 About once a week 5 Every day	1 Make it more difficult 2 Not helpful 3 Somewhat or sometimes helpful 4 Very helpful 5 Extremely helpful, I depend on them
5. Neighbours	*Yes No*	1 Almost never 2 Once a month or less 3 Between once a month and once a week 4 About once a week 5 Every day	1 Make it more difficult 2 Not helpful 3 Somewhat or sometimes helpful 4 Very helpful 5 Extremely helpful, I depend on them
6. Religious or cultural groups	*Yes No*	1 Almost never 2 Once a month or less 3 Between once a month and once a week 4 About once a week 5 Every day	1 Make it more difficult 2 Not helpful 3 Somewhat or sometimes helpful 4 Very helpful 5 Extremely helpful, I depend on them

B7. Formal Support

D7. Services Access - Please tell us about the public services and supports your child needs and has access to. For each type of service, indicate whether your child has ever needed it (yes/no), and whether he/she has actually received it (yes/no). If your child has received a certain type of service, please indicate how satisfied you have been with it.

			If Received:				
	Ever Needed?	*Ever Received?*	*Very Dissatisfied*	*Mostly Dissatisfied*	*Mixed*	*Mostly Satisfied*	*Very Satisfied*
1. Family doctor	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
2. Pediatrician	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
3. Emergency Room staff	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
4. Hospital admission	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
5. Psychiatrist	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
6. Other medical specialist (e.g. neurologist, ophthalmologist. Please specify __________)	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
7. Speech-language pathologist	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
8. Occupational therapist	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*

			If Received:				
	Ever Needed?	*Ever Received?*	*Very Dissatisfied*	*Mostly Dissatisfied*	*Mixed*	*Mostly Satisfied*	*Very Satisfied*
9. Physical therapist	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
10. Psychologist	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
11. Behaviour therapist	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
12.Case manager / service coordinator	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
13.Social worker / counselor / family therapist	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
14. Out-of-home respite care	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
15. In-home respite care	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
16. Specialized transportation services	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
17. Dentist	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
18. Chiropractor	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
19. Alternative practitioners (e.g. naturopath, homeopath, etc.)	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*
20. Other (Please specify ________________)	*Yes No*	*Yes No*	*1*	*2*	*3*	*4*	*5*

B8. Socioeconomic Status

What is the highest level of education completed?

1. Less than 7th grade
2. Junior high / Middle school (9th grade)
3. Partial high school (10th or 11th grade)
4. High school graduate
5. Partial college (at least one year)
6. College / University graduate
7. Graduate degree

What is your occupation? Please be specific (e.g., legal secretary, bank executive, truck driver)

____

B9. Social Activities

1.C6. Socializing - Compared to other families, how often do you do the following activities:					
	Much Less Than Other People	*Somewhat Less Than Other People*	*About As Much As Other People*	*Somewhat More Than Other People*	*Much More Than Other People*
1. Socialize with friends in your home	*1*	*2*	*3*	*4*	*5*
2. Socialize with friends in their homes	*1*	*2*	*3*	*4*	*5*
3. Go out on family outings (e.g., to parks, Science Centre, etc.)	*1*	*2*	*3*	*4*	*5*
4. Go out to restaurants as a family	*1*	*2*	*3*	*4*	*5*
5. Attend Church or other religious services	*1*	*2*	*3*	*4*	*5*
6. Go on vacations with children	*1*	*2*	*3*	*4*	*5*
7. Go on vacations without children	*1*	*2*	*3*	*4*	*5*

B10. Marital Satisfaction

Marital Satisfaction (if married or in long-term relationship).

Skip these 2 questions if you are single.

I5. How happy is your marriage/relationship?

1	2	3	4	5
Very unhappy	Unhappy	Mixed	Happy	Very happy

I6. How much support do you feel you receive from your spouse/partner related to caring for your child with a developmental disability?

1	2	3	4	5
Makes it more difficult	Not helpful	Somewhat or sometimes helpful	Very helpful	Extremely helpful, I depend on them