

## Family Quality of Life: Preliminary Analyses From an On-going Project

### Abstract

*This paper presents brief descriptive analyses of preliminary data gathered as part of a larger on-going project that explores quality of life in families who have one or more members with an intellectual disability. Sixty-four primary caregivers from the Greater Toronto Area were interviewed using the Family Quality of Life Survey (Brown et al., 2006). Families indicated strengths in certain life areas such as family relationships but reported challenges in other areas including support from outside the immediate family. Future research efforts and implications for service delivery and policy are discussed.*

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Family Quality of Life (FQOL) research as it relates to families with a member with an intellectual disability (ID) grew from the well established field of individual Quality of Life (QOL) for people with ID (Brown, Anand, Fung, Isaacs, & Baum, 2003). Many of the core principals and concepts of QOL have been accepted as the basis for FQOL enquiry including: holism, variability, lifespan perspective, rights and inclusion (Brown and Brown, 2004). FQOL research allows family members to identify factors that contribute to the degree to which families are able to live lives of quality.

The International Family Quality of Life project began in 1997 as an international collaboration between researchers from Canada, Israel, and Australia. The project goal was to examine the quality of life of families who have one or more members with an intellectual disability (Isaacs et al., 2007). A component of the project involved the development of a survey tool: *The Family Quality of Life Survey (FQOLS-2000)* to explore the challenges that such families face and the supports and resources needed to improve their lives. Extensive field testing of the survey in Australia, Canada, Israel, South Korea, and Taiwan resulted in the development of a revised form of the FQOLS in 2006 (FQOLS- 2006; Brown et al.,

2006). The survey addresses nine specific areas of family life: health, financial well-being, family relationships, support from others, support from disability-related services, influence of values, careers and preparing for careers, leisure and recreation, and community involvement. Each family life area is explored in relation to six key concepts: importance, opportunities, initiative, attainment, stability, and satisfaction. The survey has been translated in several languages and, currently, academic and community-based researchers in 18 countries around the world are using or are planning to use the survey. This paper presents brief descriptive analyses based on preliminary data gathered by project researchers in Toronto, Canada.

## Method

### Participants

Participants were 64 main caregivers of a family member with an intellectual disability: 55 (85.94%) mothers, 4 (6.25%) fathers, 4 (6.25%) other relationship (e.g., brother, sister, grandmother), and 1 mother and father together (1.56%). Data using the *FQOLS-2006* was collected in Toronto at MukiBaum Treatment Centres in 2006 and 2008 and at Surrey Place Centre between February and March 2008. One interviewer at each site assisted the main caregivers to complete the *FQOLS-2006*. Participants were recruited through convenience sampling (e.g., posters, mailing lists, clinician referrals).

## Results

### Description of Family Members With an ID

The 64 participants provided data on 72 persons with an ID (six participants reported having two family members with ID and one participant reported having

three family members with ID). The mean age of the person with ID was 21.67 years ( $SD=11.40$ ) with a distribution across age categories as follows: one child less than five years (1.43%), 13 children age 5-11 (18.57%), 17 youth age 12-17 (24.29%), and 39 adults over the age of 18 (55.71%). Males were slightly over-represented at 63.89% of the sample of persons with ID. The most commonly reported diagnoses were ID-cause unknown, Autism Spectrum Disorder, and dual diagnosis (i.e., developmental disability with concurrent mental health issues). The exact proportions within each diagnostic category are not reported as the reliability of reported diagnoses is unclear at this point.

### Life Areas

Mean concept scores within each of the nine areas of life were computed to provide for an overall picture of participants' perceptions of functioning, and these means were then used to rank order the nine areas of life (see Table 1). Health and family relationships were consistently ranked as high across all concepts compared to other life areas (although stability and satisfaction with health were rated relatively low). Support from others outside the immediate family (e.g., other relatives, friends, neighbours) was consistently rated the lowest compared to other life areas across all concepts. The importance of disability-related services and high levels of initiative in seeking out services were identified by participants. However, support from disability-related services was rated low relative to other life areas in terms of opportunities, attainment, and satisfaction.

A correlation matrix was also computed to explore the inter-relationships of the key concepts. The correlations among the six concepts are shown in Table 2. These correlations suggest that, if a life area is deemed important, family members

may make concerted efforts in that area (initiative). They also suggest that the existence of opportunities is positively related to families taking initiative and reporting attainment and satisfaction in life areas. Similarly, taking initiative is positively related to attainment. Attainment and satisfaction were found to be highly correlated but the degree to which these concepts are distinct from one another still needs to be determined through further analyses.

**Discussion**

This brief examination of preliminary data using the *FQOLS- 2006* in Toronto sheds light on some emerging trends in the reported quality of life of those families with a member with an intellectual disability. The results suggest that families perceive they are doing well in certain areas of life such as family relationships but experience difficulties in other areas, especially support from extended family, friends and neighbours and professional support services.

*Table 1. Rank Order and Mean Concept Scores for the Nine Areas of Life of the FQOLS-2006*

	Importance	Opportunities	Initiative	Attainment	Stability	Satisfaction
Health	1 (4.89)	3 (3.66)	2 (3.98)	2 (4.00)	7 (2.97)	6 (3.31)
Financial	4 (4.52)	8 (2.84)	4 (3.89)	8 (3.19)	7 (2.97)	7 (3.22)
Family	2 (4.77)	1 (3.97)	1 (4.31)	1 (4.31)	1 (3.26)	1 (4.08)
Supp. Oth.	9 (3.78)	9 (2.83)	9 (2.63)	9 (2.45)	6 (3.02)	8 (3.16)
Ser. Supp.	3 (4.67)	7 (2.97)	3 (3.97)	6 (3.37)	4 (3.14)	7 (3.22)
Values	6 (4.33)	4 (3.52)	7 (3.62)	3 (3.98)	5 (3.13)	2 (3.97)
Careers	7 (4.30)	6 (3.22)	6 (3.79)	5 (3.52)	2 (3.20)	4 (3.39)
Leisure	5 (4.43)	2 (3.67)	5 (3.86)	4 (3.68)	3 (3.16)	3 (3.41)
Community	8 (3.98)	5 (3.51)	8 (3.40)	7 (3.21)	4 (3.14)	5 (3.38)

*Note. Values in brackets represent mean concept scores within each life area. Supp. Oth. = Support from Others; Ser. Supp. = Service Support.*

*Table 2. Concept Correlation Matrix*

	Importance	Opportunities	Initiative	Attainment	Stability	Satisfaction
Importance	1	.12	.43**	.07	.04	-.05
Opportunities		1	.34**	.75**	.28*	.77**
Initiative			1	.53**	-.03	.27*
Attainment				1	.25	.78**
Stability					1	.32*
Satisfaction						1

\*  $p < .05$ ; \*\*  $p < .01$

As the *FQOLS- 2006* is a relatively new tool for assessing quality of life in families with a member with an intellectual disability, future efforts will focus on examining psychometric properties of the survey. The international scope of the project will allow for cross country comparisons as more international data is produced. Analyses of data emerging from use of the *FQOLS- 2006* will provide insight into some possible predictors of family quality of life in this population of families that will have implications for professional practice and government initiatives and policies addressing the issues and needs of such families.

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