

## The quantitative measurement of family quality of life: a review of available instruments

X. Hu,<sup>1,2</sup> J. A. Summers,<sup>2</sup> A. Turnbull<sup>2</sup> & N. Zuna<sup>3</sup>

<sup>1</sup> Department of Special Education, Beijing Normal University, Beijing, China

<sup>2</sup> Beach Center on Disability, University of Kansas, Lawrence, KS, USA

<sup>3</sup> The Meadows Center for Preventing Educational Risk, the University of Texas at Austin, Austin, TX, USA

### Abstract

**Background** Family quality of life (FQOL) has emerged as an important outcome of service delivery for individuals with disabilities and their families. The purpose of this review was to explore the disparity of scale development approaches between families with children with disabilities and families from other populations and identify strengths to serve as a source of recommendations to improve the measurements of FQOL in the disability field.

**Method** We conducted a keyword search of 25 databases. Sixteen measurement tools on FQOL, family well-being and family satisfaction currently used in the disability field, healthcare field and general family studies published in journals from 1980 to 2009 were included in the analysis.

**Results** Three themes emerged from the detailed analysis and comparisons of the instruments: (1) description of the primary purpose and theoretical basis; (2) identification of the tool's respondents, domains, response formats and scoring strategies to assess family systems; and (3) summarisation of available psychometric information.

**Conclusions** As family researchers continue their mission to conceptualise and theorise about FQOL, they should also promote the refinement of FQOL measurements and consider the implications from family instruments used in the healthcare and general family fields from the following aspects: (1) domains of FQOL; (2) units of analysis; (3) response format; (4) scoring choice; and (5) psychometric evaluation.

**Keywords** family quality of life, intellectual disability, measurement, quality of life

### Introduction

Family quality of life (FQOL) has become an area of considerable international interest as family-centred practices are being widely recognised and implemented in the field of intellectual disabilities (Brown *et al.* 2003; Turnbull *et al.* 2004; Aznar & Castañón 2005; R. Brown *et al.* 2006; Werner *et al.* 2009; Zuna *et al.* 2009b). Three factors have been a catalyst for the measurement of FQOL. The first is the emergence of measures of individual quality of life (QOL) that have involved ecological assessments focused on the interaction of the individual with disability with his or her living environments (Schalock *et al.* 2002; Brown & Brown 2005; Verdugo *et al.* 2005). Second, given that more and

Correspondence: Mrs Xiaoyi Hu, Beach Center on Disability, University of Kansas, 1200 Sunnyside, 3121 Haworth Hall, Lawrence, KS 66045, USA (e-mail: huxiaoyi@ku.edu).

more children and adults with intellectual disability live in their family homes rather than in institutional settings of the past (Brown *et al.* 2003; Isaacs *et al.* 2007; Petrowski *et al.* 2008; Wang & Brown 2009), enhancing the family's capacity to care for the special needs of their children with disabilities has become a higher priority. Third, FQOL measurements can enable researchers and policymakers to gain a better understanding of family well-being in order to effectively and efficiently provide supports and services to families (Bailey *et al.* 1998; Isaacs *et al.* 2007; Summers *et al.* 2007; Kober & Eggleton 2009; Wang & Brown 2009).

Although several initiatives have been conducted to measure FQOL studies by using FQOL instrument throughout the USA, Colombia, Canada, Israel, Australia and China, these instruments have not been tied to definition of FQOL. In a recent theoretical proposition paper by Zuna *et al.* (2010), FQOL is defined as 'a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact'. In a nutshell, the most unique characteristic of FQOL concept is its emphasis on examining the perceptions and dynamics of the family unit as a whole.

Research in FQOL in the disability field was originally developed utilising the concepts and constructs of individual QOL rather than general family studies (Park *et al.* 2003). At present, FQOL research focuses on three main areas: (1) conceptualisation and theory development; (2) development and modification of measurement tools; and (3) analysis of potential impacts of supports and services on improving FQOL outcomes.

Despite some progress achieved in conceptualising and measuring FQOL (Wang *et al.* 2008; Kober & Eggleton 2009; Wang & Brown 2009; Werner *et al.* 2009; Zuna *et al.* 2009b), numerous questions remain unanswered and deserve further study. The first of these challenges is how to measure FQOL using more rigorous and sound instruments. Currently, there are five instruments most commonly used to assess FQOL (i.e. the Quality of Life Questionnaire, The Family Quality of Life, the Beach Center Family Quality of Life Scale, the Family Quality of Life Questionnaire for Young Children with Special Needs, the Latin American Quality of Life Scale), but these instruments have varying

degrees of limitations and strengths (Bowman 2001; Aznar & Castañón 2005; Tang *et al.* 2005; Hoffman *et al.* 2006; Isaacs *et al.* 2007; Werner *et al.* 2009). One such problem appears to be that researchers often apply individual QOL domains and indicators when developing FQOL measures. As a result, FQOL instruments potentially lack important indicators and concepts associated with theories of family life found within other fields of family studies (e.g. family therapy, family assessment, family psychology) (Epstein *et al.* 1983; Retting *et al.* 1991; Bengston *et al.* 2005).

The current literature review focusing on quantitative measurement of FQOL outcomes had two purposes. The first purpose was to analyse the published FQOL and family satisfaction measures currently used in the disability field, healthcare field and general family studies in order to address the disparity of scale development approaches between families with children with disabilities and families from other populations.

Since the 1990s, the notion of QOL has emerged as an essential output measure for efficacy of treatment, patients' perceptions of their general health, and the quality of health care (King & Hinds 2003). With the increasing number of children with disabilities and chronic illness being enrolled in commercial and public healthcare plans, healthcare professionals have become interested in improved QOL as the ultimate outcome measure of their services, and in incorporating individual and family QOL into the decision-making process for treatment. Therefore, we included measurement tools used in healthcare field. Another field was general family studies because it is ripe with various theoretical propositions, assessment strategies and therapeutic interventions (Bengston *et al.* 2005).

The second purpose was to provide recommendations for further development of disability-related FQOL measurements by drawing strengths from measures of other fields. In line with our research interest and overarching purposes, we included family satisfaction and family well-being measurement under our examination because these two outcomes were the most prevalent ones assessed in current quantitative tools focusing on family outcomes. We define family satisfaction and family well-being as the extent to which families perceive their life status in positive instead of negative ways.

For the FQOL, family well-being and family satisfaction measures identified, analysis focused on the theoretical bases, domains, response options, scoring strategies and psychometric properties.

## Method

In order to increase searching efficiency, a three-member research team identified candidate studies through a database search.

### Criteria for article search

We conducted a keyword search of 25 databases (see Appendix 1). The keywords and combination of keywords used to search all databases included *family quality of life*, *quality of family life*, *family satisfaction and disab\** and *family well-being and disab\** (\* denotes disabled, disabling, disability or disabilities). We chose to exclude the disability term for two key phrases, family quality of life and quality of family life, because our overarching purpose was to collect articles on FQOL outside of the disability field to enrich our understanding on FQOL for all families as well as improve our current measurements on disability-related FQOL.

In addition, to search the healthcare databases, the research team chose additional terms including *life satisfaction and family*, *family and quality of life*. Finally, in order to obtain the most widely used measurements from the general family research field, we reviewed family instruments found in *Family Assessment: A Guild to Methods and Measures* (Grotevant & Carlson 1989). This reference book includes a wide variety of measures across the field of family studies and most of them are still being used in family research and practices.

We developed the following criteria for selecting research to include in this review: (1) disability-related FQOL studies published in peer-reviewed journals by using quantitative measurements; (2) healthcare studies directly relevant to family well-being and family satisfaction assessment published in peer-reviewed journals; and (3) research published in peer-reviewed journals during 1980–2009 concerning the development of tools in family satisfaction, family well-being and FQOL.

After reviewing the wide range of articles identified, we further narrowed our criteria to include only those instruments that: (1) had psychometric properties to attest to their reliability or validity; (2) focused on family assessment from the perspective of viewing the family as a whole unit; and (3) had been applied to disability-related empirical studies in the past 10 years. One exception we made in our inclusion criteria was we included all available disability-related FQOL instruments because that was the primary focus of this study. In the end, we identified 16 instruments to be included in the analysis.

## Results

Sixteen instruments met the selection criteria and were divided into three fields: disability studies, healthcare studies and general family studies (see Tables A1–3). In these tables, we highlighted general information pertaining to each instrument including: authors, purpose, theoretical base, respondent, domains, response options, scoring techniques, number of items, and psychometric properties. Moreover, Table A3 included references illustrating studies in which the general family measurements have been used with a disability population. Three themes emerged from the detailed analysis and comparisons of the instruments from these three fields: (1) description of the background information, primary purpose and theoretical basis of the tool development; (2) identification of the tool's respondents, domains, response formats and scoring strategies to assess family systems; and (3) summarisation of available psychometric information.

### Theoretical base and scale purpose

The first theme that emerged was the theoretical basis and primary purpose of measurements (see Tables A1–3, Column 2). FQOL tools from these three fields demonstrated varying conceptual frameworks and application intentions.

#### *Disability studies*

Five instruments were included in disability-related FQOL measurement tools. The first one came from Bowman's (2001) doctoral dissertation (see

Table A1, Column 2). However, because Bowman developed the Quality of Life Questionnaire from a theoretical model of individual QOL related to paediatric chronic disease and disability, the questionnaire placed more importance on assessing children's development, instead of FQOL. Secondly, a team of Canadian and international researchers developed The Family Quality of Life Survey (FQoLS) by collecting suggestions and recommendations from international stakeholders (Isaacs *et al.* 2007). Meanwhile, researchers developed the Beach Center Family Quality of Life (FQOL) Scale as a result of an extensive qualitative investigation and three national field tests of families' level of satisfaction with various aspects of FQOL (Park *et al.* 2003; Summers *et al.* 2005; Hoffman *et al.* 2006). FQoLS and FQOL Scale have been translated into several languages and widely used in several countries. The fourth instrument, the Family Quality of Life Questionnaire for Young Children with Special Needs (FQOLQ-YCSN) from Taiwan used the domains of the Beach Center FQOL Scale and Canadian FQoLS for its construct foundation (Tang *et al.* 2005). The last instrument was the Latin American Quality of Life Scale developed by Argentinean researchers, which has been translated to English and Indian and widely utilised in Latin countries (Aznar & Castañón 2005). According to Table A1, the purposes for developing FQOL scales were twofold: (1) to obtain data about families' perceptions of various facets of family life with children with disabilities and (2) to assist policymakers in evaluating family services and supports. Aznar & Castañón (2005) proposed a topological model of QOL to examine the material, personal and social aspects change within the context of FQOL. Although these five disability-related FQOL scales have a focus on the complex and mutual impacts of both children with disabilities and other family members, they do not state their theoretical base explicitly. Moreover, none of the instruments originated from a well defined conceptual framework or theory from the field of family studies.

#### *Healthcare studies*

As we noted earlier, increasing interest has been focused on improving QOL of parents and children

with disabilities in healthcare agencies/programmes. Along with it, numerous QOL measurements pertinent to specific populations have been developed and used to identify patients' and family caregivers' satisfaction with health care and their perceptions of how illness impacts family life (Wertlieb 2003) (see Table A2, Column 2). The proliferation of health-related QOL instruments illustrates the interest within the profession to move health care towards a more person-centred approach. Meanwhile, efforts to improve the quality of health care have emphasised FQOL-related surveys. Four measurements met our criteria including the Multidimensional Assessment of Parental Satisfaction for Children with Special Needs (MAPS), Revised Impact on Family Scale, Family Dermatology Life Quality Index, and Quality of Life in Life Threatening Illness – Family Carer Version (Stein & Riessman 1980; Ireys & Perry 1999; Basra *et al.* 2006; Cohen *et al.* 2006).

As indicated in Table A2, MAPS was focused on families' satisfaction with extra-familial supports, such as care coordination and family-centred care. The purpose of each of the remaining three scales was to explore the impact of different diseases on FQOL. Although some of the scales did not describe their conceptual or theoretical framework, the foundations of these instruments appeared to originate from family adaptation theory which calls for a new level of balance, coherence and functioning to a stressful or crisis situation (McCubbin & McCubbin 1993).

#### *General family studies*

Measures of the more general field of family studies have been developed to assess various aspects of family life (see Table A3, Column 2). Seven family assessment tools met the selection criteria for the current study. Although some dated back to the 1980s, researchers still apply them to current studies of families with children with and without disabilities (e.g. Warfield *et al.* 2000; Trute 2003; Nachshen & Minnes 2005; Lewis *et al.* 2006). This trend demonstrated that, on the one hand, these instruments had good applicability to families with children with disabilities; on the other hand, there was a lack of family instruments within the disability field to examine variables that explain FQOL as

an outcome. The seven selected instruments were derived from a variety of theories. Four well specified family models (i.e. Circumplex Model of Marital and Family Systems, McMaster Model of Family Functioning, Process Model of Family Functioning, and T-Double ABCX Model of Family Adjustment and Adaptation) were the theoretical base of five of the reviewed instruments [i.e. Family Adaptability and Cohesion Evaluation Scales IV (FACES IV), Family Assessment Device, Family Assessment Measure, Family Member Well-Being Index, and Family Satisfaction Survey] (McCubbin & Patterson 1982; Olson & Wilson 1982; Epstein *et al.* 1983; Skinner *et al.* 1983; Olson *et al.* 2007). The remaining two measures, Family Environment Scale and Family APGAR, were based on general family systems theory (Smilkstein 1978; Moos & Moos 2002). However, these theories did not address family life cycle sufficiently, which sought to explain how a family changes at different life stages (Carter & McGoldrick 1999; Turnbull *et al.* 2006).

### Scale properties

In addition to the theoretical basis of the measurement development, another consistent theme was their various scale characteristics, including the tool's respondents, domains, response formats and scoring strategies (see Tables A1–3, Columns 3–5).

### Disability studies

One common feature of most disability-related FQOL instruments (excluding Bowman 2001 and Aznar & Castañón 2005) was the focus on assessing the whole family as the unit of analysis, even though the respondents were individual family members and primarily parents or mothers (see Table A1, Columns 3 and 4). This whole-family perspective appeared because of the fact that researchers' primary intention of conducting FQOL studies was to investigate 'the impact of the person with disability on the family and family structure, and particularly on the impact of disability services on overall FQOL' (Isaacs *et al.* 2007, p. 179).

With regard to response format, the Latin American Quality of Life Scale adopted frequency as its response choice. The remaining four scales adopted

a traditional satisfaction Likert 5-point rating as the primary format (Verdugo *et al.* 2005) (see Table A1, Column 5). In addition to satisfaction, FQoLS and FQOLQ-YCSN also asked respondents to respond to each item with Likert ratings on constructs, including importance and frequency. The five scales have relied on mean scores or sum score for each domain as the scoring approach. The FQoLS also included sections in each domain for open-ended responses.

### Healthcare studies

Generally speaking, the healthcare FQOL scales have been more child-oriented with a focus on specific diseases, as contrasted to the holistic family-oriented perspective (see Table A2, Column 3). They have emphasised both the impact of the individual's health condition on the family, and coping and adjustment strategies used by family members. The scales' respondents include the patients' primary family caregivers or immediate family members. This has been particularly the case for the Quality of Life in Life Threatening Illness – Family Carer Version, whose source of data came from primary family caregivers (Cohen *et al.* 2006). In addition, the domains assessed were either impact of disease or extra-family care supports (see Table A2, Column 4). For instance, the domains and indicators of the Family Dermatology Life Quality Index have been concerned about the impact of skin disease on health-related QOL of family members (Basra *et al.* 2006).

Overall, the healthcare FQOL scales have been relatively homogeneous; however, the response formats and scoring techniques have varied (see Table A2, Column 5). For example, MAPS (Ireys & Perry 1999) used a bipolar-adjective Likert format (i.e. a rating scale approach in which adjective pairs are presented in a dichotomous line) that involved adjectives depicting two extreme ratings. This method has been an alternative to a satisfaction numerical rating format. Cohen *et al.* (2006) integrated multiple rating-based response approaches into Quality of Life in Life Threatening Illness. These response choices included frequency, bipolar-adjective, identification and satisfaction. Additionally, other scoring strategies replaced the raw score mean scaling method. For example, MAPS adopted

the percentage method for scoring instead of mean score in order to avoid the potential skewness, which has often occurred in satisfaction scales (Ireys & Perry 1999). More specifically, the per cent of respondents' judgement on 'Excellent' or 'Poor' on each item has been calculated to evaluate the quality of services provided by medical professionals. An example is the study of Liptak *et al.* (2005), which uses MAPS to evaluate the perceptions of families of children with developmental disabilities regarding primary care physicians. This amount of detail is not presented for other measures.

#### *General family studies*

Based on their respective theoretical orientations, the seven general family measures have attempted to capture the most fundamental elements related to family dynamics (see Table A3, Column 4), including cohesion (e.g. closeness), adaptability (e.g. system maintenance and problem solving), communication (e.g. expressiveness) and role performance (e.g. personal growth and task accomplishment). All of the scales have identified that their unit of analysis was the whole family; however, the scales have had various requirements pertaining to respondents (see Table A3, Column 3). For example, each family member was to complete the FACES IV (Olson *et al.* 2007); however, individual family members could complete the Family APGAR and Family Member Well-Being Index as representative of the entire family's satisfaction and well-being (Smilkstein 1978; McCubbin & Patterson 1982). However, even in the case of FACES IV, where more than one family member completed the measure, no strategies have been given for aggregating the individual scores to obtain a single score representing the whole family.

With regard to response format, six measures have adopted the traditional Likert format for satisfaction, frequency and identification (see Table A3, Column 5). The newest version of FACES IV has used bipolar rating to replace the 5-point format from the previous three versions in order to obtain positive and negative directions and degrees (Olson *et al.* 2007). The remaining measurement tool, Family Environment Scale – Third Edition (FES), has used a true–false format (Moos & Moos 2002). In addition to the response format, the scoring

techniques of FES and FACES IV have been distinct from the scoring methods in other family measures. They both have converted raw scores into standard scores and then depicted scores on a graphic profile form to present the current family life status (Moos & Moos 2002; Olson *et al.* 2007). The other five measures have used either summed scores or the mean score of domains as their scoring methods.

#### *Psychometric characteristics*

The last theme was psychometric features. Sufficient data on validity and reliability typically are viewed as essential elements for determining measurement quality (Levin 1999). According to standards for psychometric properties, internal consistency (coefficient  $\alpha$ ) and test–retest reliability coefficients being greater than 0.70 are considered as sound reliability properties (Nunnally 1978). In addition, evidence of concurrent validity (i.e. the degree to which the measure correlates with other measures of the same construct that are measured at the same time) is also utilised as one psychometric criterion for well established FQOL measurements.

#### *Disability studies*

Except the Latin American Quality of Life Scale, all other FQOL scales in the disability field have reported psychometric information (see Table A1, Column 6). More specifically, the Beach Center FQOL Scale and FQoLS have reported sound reliability and validity because their internal consistency is above 0.70. Moreover, all of the scales have provided sufficiently detailed manuals that have allowed for critical evaluation and replication. Additionally, the Beach Center FQOL Scale and the FQoLS have been reported in peer-reviewed articles (Hoffman *et al.* 2006; Wang *et al.* 2006; Isaacs *et al.* 2007; Summers *et al.* 2007; Werner *et al.* 2009). The Beach Center FQOL Scale has demonstrated concurrent validity with specified sub-scales to other existing measures; specifically, the *Family Interaction* sub-scale was convergent with the Family APGAR ( $r = 0.68, P < 0.001$ ) and the *Emotional Well-Being* sub-scale was convergent with the Family Resources Scale (Dunst & Leet 1985) ( $r = 0.60, P < 0.001$ )

(Hoffman *et al.* 2006). Moreover, Zuna *et al.* (2009a) demonstrated that by conducting a confirmatory factor analysis, the kindergarten children without disabilities also indicated adequate fit to the theoretical model of the Beach Center FQOL Scale.

#### *Healthcare studies*

Detailed psychometric properties were reported on four healthcare scales (see Table A2, Column 6). The internal consistency across the four instruments was greater than 0.75, indicating well established reliability. Moreover, researchers pursued instrument refinements. For instance, Stein & Jessop (2003) demonstrated that one robust factor produced a revised Impact on Family Scale to replace an earlier version. However, no detailed data were reported on scales' validity.

#### *General family studies*

Among general family measurements, five tools qualified as having a well established psychometric evaluation standard of reliability with coefficient alpha arranged from 0.61 to 0.95 (Smilkstein 1978; Olson & Wilson 1982; Epstein *et al.* 1983; Moos & Moos 2002; Olson *et al.* 2007) (see Table A3, Column 6). Two measures, FACES IV and the Family Assessment Device, presented convergent validity with other scales (Moos & Moos 2002; Olson *et al.* 2007). In addition to the psychometric information on reliability and validity, the authors have published manuals for administration and scoring (McCubbin & Patterson 1982; Olson & Wilson 1982; Moos & Moos 2002).

Furthermore, researchers have used these general family assessment tools to assess disability populations. Some of these instruments have demonstrated good psychometric characteristics. For instance, Underhill and colleagues investigated family satisfaction with survivors of traumatic brain injury. They reported that the reliability coefficient for the Family Satisfaction Scale ranged from 0.94 to 0.95, with evidence of convergent validity with the Life Satisfaction Index – A (Underhill *et al.* 2004). Margalit & Kleitman (2006) found that the FACES III showed a coefficient alpha of 0.69 in their studies of mothers' resilience in families whose infants with developmental disabilities were participating in early intervention programmes. Trute (2003) reported

that coefficient alpha was 0.84 for two separate sets of surveys from Family Assessment Measure. However, other authors of other empirical studies did not report psychometric information related to disability samples (e.g. Nachshen & Minnes 2005; Lewis *et al.* 2006; Chen & Clark 2007).

## **Discussion**

This study identified 16 family instruments that subjectively have measured perspectives of FQOL, family well-being and family satisfaction. The findings were encouraging for use in research with disability samples. This section will address the following five issues: (1) domains of FQOL; (2) units of analysis; (3) response format; (4) scoring choice; and (5) psychometric evaluation.

### **Domains of family quality of life**

The disability-related FQOL measures have demonstrated varying strengths and weaknesses. More specifically, the domains assessed are more comprehensive than those in healthcare studies because of the fact that healthcare FQOL instruments limit their domains to the impact of specific disease on family functioning, as well as adaptability strategies of family members. In a recent review comparing the FQoLS and FQOL Scale, Rillotta and her colleagues (2010) demonstrate that while both surveys were found to assess a relatively comprehensive FQOL data, some components relevant to FQOL were included in one survey but not the other. However, all disability-related FQOL instruments lack some important domains that are addressed in measures of general family assessment. For instance, family organisation has been one of the key domains widely assessed in general family tools (e.g. *Role Performance* in the Family Assessment Device, *Organisation Control* in the FES). Another domain neglected in the disability-related measures has been family dynamics (e.g. *Cohesion and Flexibility* in FACES IV, *Adaptation* in Family APGAR), which emphasises the complex reciprocal interaction either among family members (except *Family Interaction* of the Beach Center FQOL Scale) or between the family unit and outside family services as well supports to meet families' various

needs (e.g. family satisfaction with the behavioural training) (Zuna *et al.* 2009b).

One reason for the discrepancy of key domains is that disability-related FQOL measures have been developed without the authors addressing the definitional and theoretical bases of the FQOL construct (Hoffman *et al.* 2006; Isaacs *et al.* 2007; Zuna *et al.* 2010). Another possible reason is most scale developers define FQOL as a multidimensional construct in a functional sense of family activities and responsibilities. This functional orientation arises from the same orientation leading to the dimensions of individual QOL which can 'be reliably observed and appear to be universally held' (Schalock *et al.* 2002, p. 461). The functional orientation has been explicitly rooted in current FQOL measurement tools that have attempted to break down the FQOL construct into constituent domains. Although functional assessments of FQOL indicators are objective, performance-oriented, and more easily operationalised for evaluation across groups, they lack a conceptual framework comprising concepts, variables and domains, as well as the relationships among variables necessary for theory building regarding FQOL research (Schalock *et al.* 2002).

In contrast, in general family studies, many of the reviewed family instruments derive strength from their systematic and well specified conceptual frameworks or family theories. A conceptual framework or theory is essential to build the construct domains and indicators of an assessment measure (Bengston *et al.* 2005). Only the Latin American Quality of Life Scale (Aznar & Castañón 2005) introduced a conceptual framework; however, it is more individual QOL-oriented than FQOL-oriented. Fortunately, researchers are actively engaged in the theorising process to propose a unified theory to predict and explain FQOL outcomes (Zuna *et al.* 2009b, 2010). Another way to address the lack of connection to established family theory is to create a new sub-scale or add a domain reflecting family dynamics in current FQOL scales to assess the interactions between parents and children and transactions among family members, as well as their synchrony, reciprocity and patterns of mutual influence. In addition, this domain will assist researchers to better understand how these patterns affect family cohesion and intimacy,

distribution of power in the family, decision making, family flexibility, and family competence and adjustment.

### Unit of analysis

Although theoretical models are absent in disability-related FQOL studies, researchers agree on the underlying concept that factors associated with individuals with disability and families interact. Assessing all family members will provide more robust data to describe family life, establish psychometric properties of the measures, and refine and improve research methods. Consequently, FQOL measurement has been focusing on the whole family as the unit of analysis. This holistic perspective is one of the selection criteria for this review. The problem here is the discrepancy between the stated unit of analysis and respondent. As illustrated in Table A1, the five FQOL instruments still chose individual family member or parents as their primary respondents to assess whole family functioning. It is unclear whose outcome is being reported, the individual respondent or multiple family members. Indeed, a major methodological problem in FQOL research is the heavy reliance on mothers as the sole source of data. This is due to the fact that traditionally mothers are seen as the main caregivers who know the most about the way their family functions and therefore are more available to participate in family-related studies. Wang *et al.* (2006) recognised this challenge of respondent burden and the lack of independence of respondents when using paper-pencil, mail-delivered survey. The method of using an individual family member as the data source, also referred to as the 'most apparent weakness of family research' (Larson 1974, p. 124), is contradictory with the original target of measuring FQOL of the whole family unit. Consequently, researchers should take sufficient caution when analysing and generalising results to the family unit when only one or two family members have completed the instrument.

General family instruments have encountered the same dilemma. As depicted in Table A3, the same inconsistency exists. For instance, all seven general family instruments state the respondent should be an individual family member. Alternatively, health-care instruments collect data from parents or other

immediate family members accompanying patients in order to evaluate family life (e.g. Stein & Jessop 2003). Researchers have developed different versions of scales on dyadic relationship (e.g. three versions of Family Assessment Measure: general studies, dyadic studies and individual family member; version for couples without children living at home in FACES IV). Thus, researchers have made efforts to involve multiple family informants in studies so that results do not reflect simply one family member's perspective. For example, in a factor analysis of the Family Dermatology Life Quality Index, Basra *et al.* (2006) chose 59 family members, including parents, spouses, sons, daughters and grandparents as primary respondents.

Based on the review of healthcare and general family measures, there are three approaches to enhancing disability-related FQOL measurements of the family as a unit of analysis. First, researchers need to pay particular attention to all family members by obtaining data from multiple family informants to get a comprehensive picture of the family as a whole. Second, developing specific versions of measures for various family sub-systems is another feasible approach. In this way, researchers can obtain family data in multiple life stages from a developmental perspective (e.g. families in transition stage). This is particularly the case for the latest version of FACES IV. This version is actually an evaluation package encompassing three scales based on the first version published in 1979 (Olson *et al.* 1979). Researchers and practitioners can choose the specific tool to accomplish their research goals. With regard to the complicated constructs and holistic purpose of FQOL, researchers can develop more versions or sub-scales for multiple uses. The last approach is to obtain long-term data about FQOL. In general family assessment studies, individual respondents need to complete the FACES IV twice (i.e. before and after the intervention or counselling of family therapists). Furthermore, analytical techniques including repeated-measures analysis of variance or multivariate analyses are potential strategies to aggregate individual scores and to study the discrepancy between members in a family (Lewis *et al.* 2006). In this way, researchers can collect more information on how changes impact families' present and future states to compensate for the lack of multiple family

informants as well as to compare the differences within a family unit. This approach also has potential implications not only for disability-related family researchers, but also for policymakers in developing future family support policies and practice. For instance, specific services can be developed according to family's unique needs to enhance the FQOL. Moreover, professionals can better coordinate with family members to discuss their own problems, identify solutions and secure resources.

### Response formats

Family quality of life studies accentuate life satisfaction, a significant subjective variable, because it can reflect how a family member feels and how she or he experiences life (Hensel 2001). Other advantages of using satisfaction as an indicator of individuals' perceived QOL include comparing population samples, providing a common language and evaluating consumer needs and services provided (Felce & Perry 1995; Schalock 2000). Most disability-related FQOL scales use satisfaction as a key concept in their response format (i.e. 1 = very dissatisfied, 3 = neither satisfied nor dissatisfied and 5 = very satisfied). Although FQoLS and FQOLQ-YCSN attempt to assess FQOL from other perspectives including attainment (i.e. the degree to which the family is able to accomplish things that it wants) or initiative (i.e. the degree to which the family takes advantage of available opportunities with or without outside support), they still use the same Likert rating method to assess families' satisfaction condition (satisfaction, i.e. the overall perception of family life).

A limitation of disability-related FQOL instruments is the lack of response variability because focusing only on satisfaction may limit other dependent measures of QOL (Cummins 1996). In fact, equating QOL solely with personal satisfaction and therefore taking this statement as the acceptability of one's life conditions for granted has been a target of critique. For instance, Edgerton (1990) stated that life changes may not impact family life and routines immediately. He further argued that significant life events may execute temporary changes in their current satisfaction level, but recovery in subjective well-being will occur in a long term. In addition, it may be impossible to

assess expressions of satisfaction with family life without consideration of the context in which they live (Turnbull *et al.* 2006). Therefore, satisfaction with family life as the sole response choice, without regard to widely different life conditions and contexts, can threaten the validity of FQOL measures.

As illustrated in Tables A2 and A3, healthcare and general family assessment tools collect data beyond a sole satisfaction format. These various formats focus on evaluating family satisfaction using alternative formats such as a frequency-based format, bipolar rating format (i.e. -5 to +5), identification evaluation format (i.e. not a problem or huge problem), agree-disagree Likert, and dichotomous format (i.e. true or false). One of the major changes in the latest FACES IV is the bipolar Likert format to replace the former unipolar rating format (Olson *et al.* 2007). Additionally, some measures integrate multiple formats into their scales to increase the response variability as much as possible (e.g. Cohen *et al.* 2006).

This review offers significant implications for improving disability-related FQOL scales. First, researchers should attempt to blend the current satisfaction rating format with other format styles to avoid respondents' weariness and self-awareness. For instance, a 5-point anchored response on judging the service (i.e. 1 = does not apply, 3 = good and 5 = excellent) can replace the satisfaction rating format in *Disability-related Support* domain of the Beach Center FQOL Scale. The frequency-based 5-point format in the Family APGAR (i.e. 1 = never, 3 = some of the time and 5 = always) is another alternative choice for indicators of *Family Relationship* domain of FQoLS. Additionally, in view of the heterogeneity of families with children with disabilities and the limited family measures on this population, it is essential for FQOL researchers to examine family members' preferences on response formats to increase the response variability. Finally, open-ended questions can be added into FQOL scales; interviews and observation checklists can also be used as supplements to provide a different window into family dynamics.

### Scoring choices

The findings of this review demonstrate two main trends in FQOL tools. One is the summative score

adding all the sub-scales to obtain a total score. Another is the family mean score approach, averaging the summative approach into a single mean score. Both approaches enable researchers to make comparisons among families with different numbers of members and portray the present family life status. Nevertheless, the two primary approaches have the same drawback of reducing score variance, therefore reducing the statistical conclusion of validity in subsequent analyses. Only one measurement, MAPS, calculates the percentage of respondents to report their satisfaction and dissatisfaction.

Researchers in general family assessment studies have recommended using additional statistical and graphic analyses after either mean scores or summative scores are obtained (Neabel *et al.* 2000). Three measures have used extra scoring strategies to modify their data (e.g. FACES IV, FES, Family Assessment Measure). The authors have suggested converting the scores to standard scores and then plotting onto a graphic compartmentalised profile of the theoretical model in order to demonstrate the family life status. However, scale developers need to be aware that graphic presentations are more appropriate for clinical application as a diagnostic tool for family therapists as contrasted to FQOL measurement intended to serve as an outcome measure in a research or programme evaluation.

There are two approaches to improve disability-related FQOL measurements. One approach is to utilise different scoring methods on the current domains of FQOL. For instance, one strategy is to adopt the percentage choice used in MAPS in *Disability-related Services* of the Beach Center FQOL Scale in order to calculate families' satisfaction with specific services or supports. Another way is to use multiple regression, covariance-based scoring techniques and cluster analysis to interpret family data and find complicated family patterns (Schumm 1982). These methods have been widely used in general family studies and demonstrate satisfying psychometric properties (e.g. Underhill *et al.* 2004; Herring *et al.* 2006; Chen & Clark 2007; Lightsey & Sweeney 2008).

### Psychometric evaluation

The measures reviewed have many positive qualities and strengths related to psychometric properties.

Many of the general family instruments have sound theoretical models. Furthermore, some of the measures have training manuals explaining the scoring method and administration procedure (e.g. McCubbin & Patterson 1982; Moos & Moos 2002). In comparison with these measures, only one measure has both reliability and validity information (i.e. the Beach Center FQOL Scale). Canadian and Argentinean researchers are in the process of examining the validity and reliability of FQoLS (Aznar & Castañón 2005; Petrowski *et al.* 2008; Wang *et al.* 2008; Werner *et al.* 2009). To advance the evidence base of FQOL measures relevant to the field of disability, researchers should report the internal consistency of the responses collected on the measure for the sample on which they are reporting. As demonstrated in this review, internal consistency is not a stable characteristic of a measure and may vary from one sample to the next. More importantly, developers of FQOL measures need to explore and report their measure's psychometric properties.

## Conclusion

The family is perhaps the most important social context within which disability occurs. In recent years, researchers and professionals have moved towards family-centred services under a strength-based support paradigm, reflecting philosophical, practical and evidence-based commitments to the understanding of children's outcomes as a function of family outcomes (Turnbull *et al.* 2007). Researchers have recognised FQOL assessment as a challenging endeavour, yet vital in the pursuit of increasing knowledge within the disability field (Hoffman *et al.* 2006; Mannan *et al.* 2006). As family researchers continue their mission to conceptualise and theorise about FQOL, they should also promote the refinement of FQOL measurements and consider the implications from family instruments used in the healthcare and general family fields.

In summary, the five disability-related FQOL instruments described in this review are all effective tools for evaluating the current status of FQOL, focusing on either family member's individual QOL, the perception of satisfaction, the availability

of obtaining outside and inside family support, and/or ability to enhance the family cohesion and adaptability more effectively. Further investigation into the instruments' domains, response formats, scoring choices and psychometric properties highlights the need to refine FQOL scales. In addition, 12 family measurements from the healthcare field and general family studies demonstrate a variety of unique strengths. In order to contribute to FQOL of families with children with disabilities, researchers must identify and incorporate strengths found in other fields to refine FQOL measurements. This review will promisingly be a resource for disability-related researchers as they strive to enhance the scientific merit of FQOL measures.

## References

- Aznar A. S. & Castañón D. G. (2005) Quality of life from the point of view of Latin American families: a participative research study. *Journal of Intellectual Disability Research* **49**, 784–8.
- Bailey D. B., McWilliam R. A., Darkes L. A., Hebbeler K., Simeonsson R. J., Spiker D. *et al.* (1998) Family outcomes in early intervention: a framework for program evaluation and efficacy research. *Exceptional Children* **64**, 313–28.
- Basra M. K., Sue-Ho R. & Finlay A. Y. (2006) The Family Dermatology Life Quality Index: measuring the secondary impact of skin disease. *British Journal of Dermatology* **156**, 528–38.
- Beach Center on Disabilities (2006) *Family Quality of Life Scale*. Beach Center on Disabilities, Lawrence, KS, USA.
- Bengston V. L., Acock A. C., Allen K. R., Dilworth-Anderson P. & Klein D. M. (2005) *Sourcebook of Family Theory & Research*. Sage Publications, Thousand Oaks, CA, USA.
- Bowman R. A. (2001) Quality of life assessment for young children with developmental disabilities and their families: development of a quality of life questionnaire. Theses (PhD), West Virginia University.
- Brown I., Anand S., Isaacs B., Baum N. & Fung W. L. (2003) Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities* **15**, 207–30.
- Brown I., Brown R. I., Baum N. T., Isaacs B. J., Myerscough T., Neikrug S. *et al.* (2006) *Family Quality of Life Survey General Version*. Surrey Place Centre, Toronto, Canada.
- Brown R., MacAdam-Crisp J., Wang M. & Iarocci G. (2006) Family quality of life when there is a child with

- a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities* **3**, 238–45.
- Brown R. I. & Brown I. (2005) The application of quality of life. *Journal of Intellectual Disability Research* **49**, 718–27.
- Carter B. & McGoldrick M. (eds) (1999) *The Expanded Family Cycle: Individual, Family, and Social Perspectives*. Allyn & Bacon, Needham Hill, MA, USA.
- Chen J. Y. & Clark M. J. (2007) Family function in families of children with Duchenne muscular dystrophy. *Family & Community Health* **30**, 296–304.
- Cohen R., Leis A. M., Kuhl D., Charbonneau C., Ritvo P. & Ashbury F. D. (2006) QOLLTI-F: measuring family carer quality of life. *Palliative Medicine* **20**, 755–67.
- Cummins R. A. (1996) The domains of life satisfaction: an attempt to order chaos. *Social Indicators Research* **38**, 303–28.
- Dunst C. J. & Leet H. E. (1985) *Family Resource Scale: Reliability and Validity*. Winterberry Press, Asheville, NC, USA.
- Edgerton R. B. (1990) Quality of life from a longitudinal research perspective. In: *Quality of Life: Perspectives and Issues* (ed. R. L. Schalock), pp. 149–60. American Association on Mental Retardation, Washington, D.C.
- Epstein N. B., Baldwin L. M. & Bishop D. S. (1983) The McMaster family assessment device. *Journal of Marital and Family Therapy* **9**, 171–80.
- Felce D. & Perry J. (1995) Quality of life: its definition and measurement. *Research in Developmental Disabilities* **16**, 51–74.
- Grotevant H. D. & Carlson C. I. (1989) *Family Assessment: A Guide to Methods and Measures*. The Guilford Press, New York, NY, USA.
- Hensel E. (2001) Is satisfaction a valid concept in the assessment of quality of life of people with intellectual disabilities? A review of the literature. *Journal of Applied Research in Intellectual Disabilities* **14**, 311–26.
- Herring S., Gray K., Taffe J., Tonge B., Sweeney D. & Einfeld S. (2006) Behavior and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research* **50**, 874–82.
- Hoffman L., Marquis J., Poston D., Summers J. A. & Turnbull A. (2006) Assessing family outcomes: psychometric evaluation of the Beach Center family quality of life scale. *Journal of Marriage and Family* **68**, 1069–83.
- Ireys H. T. & Perry J. J. (1999) Development and evaluation of a satisfaction scale for parents of children with special health care needs. *Pediatrics* **104**, 1181–91.
- Isaacs B. J., Brown I., Brown R. I., Baum N., Myerscough T., Neikrug S. *et al.* (2007) The international family quality of life project: goals and description of a survey tool. *Journal of Policy and Practice in Intellectual Disabilities* **4**, 177–85.
- King C. R. & Hinds P. S. (eds) (2003) *Quality of Life: From Nursing and Patient Perspectives*. Jones & Bartlett Publishers, Sudbury, MA, USA.
- Kober R. & Eggleton I. R. C. (2009) Using quality of life to evaluate outcomes and measure effectiveness. *Journal of Policy and Practice in Intellectual Disabilities* **6**, 40–51.
- Larson L. E. (1974) System and subsystem perception of family roles. *Journal of Marriage and Family* **36**, 123–38.
- Levin I. P. (1999) *Relating Statistics and Experimental Design*. Sage Publications, Newbury Park, CA, USA.
- Lewis P., Abbeduto L., Murphy M., Richmond E., Giles N., Bruno L. *et al.* (2006) Psychological well-being of mothers and youth with fragile X syndrome: syndrome specificity and within-syndrome variability. *Journal of Intellectual Disability Research* **50**, 894–904.
- Lightsey O. R. & Sweeney J. (2008) Meaning in life, emotional-oriented coping, generalized self-efficacy, and family cohesion as predictors of family satisfaction among mothers of children with disabilities. *The Family Journal* **16**, 212–21.
- Liptak G. S., Orlando M., Yingling J. T., Kaufman K. L., Maley D. P., Tompkins L. A. *et al.* (2005) Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of Pediatric Health Care* **20**, 245–51.
- Lusting D. C. & Akey T. (1999) Adaptation in families with adult children with mental retardation: impact of family strengths and appraisal. *Education and Training in Mental Retardation and Developmental Disabilities* **34**, 260–70.
- Mannan H., Summers J. A., Turnbull A. P. & Poston D. J. (2006) A review of outcome measures in early childhood programs. *Journal of Policy and Practice in Intellectual Disabilities* **3**, 219–28.
- Margalit M. & Kleitman T. (2006) Mothers' stress, resilience and early intervention. *European Journal of Special Needs Education* **21**, 269–83.
- McCubbin H. I. & Patterson J. (1982) Family member well-being scale. In: *Family Assessment: Resiliency, Coping and Adaptation-Inventories for Research and Practice* (eds H. I. McCubbin, A. I. Thompson & M. A. McCubbin), pp. 753–82. University of Wisconsin System, Madison, WI, USA.
- McCubbin M. A. & McCubbin H. I. (1993) Families coping with illness: the resiliency model of family stress, adjustment, and adaptation. In: *Families, Health, & Illness: Perspectives of Coping and Intervention* (eds C. Danielson, B. Hamell-Bissell & P. Winstead-Fry), pp. 21–63. Mosby Publishing Company, St. Louis, MO, USA.

- Moos R. H. & Moos B. S. (2002) *Family Environment Scale Manual*. Mind Garden Inc., Menlo Park, CA, USA.
- Nachshen J. S. & Minnes P. (2005) Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research* **49**, 889–904.
- Neabel B., Bourbonnais F. F. & Dunning J. (2000) Family assessment tools: a review of the literature from 1978–1997. *Heart & Lung* **29**, 196–209.
- Nunnally J. C. (1978) *Psychometric Theory*. McGraw-Hill, New York, NY, USA.
- Olson D. H. & Wilson R. (1982) Family satisfaction scale. In: *Family Inventories* (eds D. H. Olson, H. I. McCubbin, H. Barnes, A. Larsen, M. Muxen & M. Wilson), pp. 89–103. Life Innovations, Minneapolis, MN, USA.
- Olson D. H., Sprenkle D. H. & Russell C. (1979) Circumplex model of marital and family systems: cohesion and adaptability dimensions, family types, and clinical application. *Family Process* **18**, 3–28.
- Olson D. H., Gorall D. M. & Tiesel J. W. (2007) *FACES IV and the Circumplex model: Validation Study*. Available at: <http://www.facesiv.com/pdf/2.development.pdf> (retrieved 20 September 2009).
- Park J., Hoffman L., Marquis J., Turnbull A. P., Poston D., Mannan H. *et al.* (2003) Toward assessing family outcomes of service delivery: validation of a family quality of life survey. *Journal of Intellectual Disability Research* **47**, 367–84.
- Petrowski N. T., Edwards M., Isaacs B. J., Baum N. & Brown I. (2008) Family quality of life: preliminary analyses from an on-going project. *Journal on Developmental Disabilities* **14**, 111–14.
- Retting K. D., Danes S. M. & Bauer J. W. (1991) Family life quality: theory and assessment in economically stressed farm families. *Social Indicators Research* **24**, 63–93.
- Rillotta F., Kirby N. & Shearer J. (2010) A comparison of two family quality of life measures: an Australian study. In: *Enhancing Quality of Life for People with Intellectual Disabilities: From Theory to Practice* (ed. R. Kober), pp. 305–48. Springer Publishing, Dordrecht, Netherlands.
- Schalock R. L. (2000) Three decades of quality of life. *Focus on Autism and Other Developmental Disabilities* **15**, 116–27.
- Schalock R. L., Brown I., Brown R., Cummins R. A., Felce D., Matikka L. *et al.* (2002) Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: report of an international panel of experts. *Mental Retardation* **40**, 457–70.
- Schumm W. R. (1982) Integrating theory, measurement and data analysis in family studies survey research. *Journal of Marriage and the Family* **44**, 983–98.
- Skinner H. A., Steinbauer P. D. & Santa-Barbara J. (1983) The family assessment measure. *Canadian Journal of Community Mental Health* **2**, 91–105.
- Smilkstein G. (1978) The Family APGAR: a proposal for a family function test and its use by physicians. *Journal of Family Practice* **6**, 1231–9.
- Stein R. E. K. & Jessop D. J. (2003) The Impact on Family Scale revisited: further psychometric data. *Journal of Developmental and Behavioral Pediatrics* **24**, 9–16.
- Stein R. E. K. & Riessman R. K. (1980) The development of an Impact on Family Scale: preliminary findings. *Medical Care* **18**, 456–72.
- Summers J. A., Poston D., Turnbull A. P., Marquis J., Hoffman L., Mannan H. *et al.* (2005) Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research* **49**, 777–83.
- Summers J. A., Marquis J., Manna H., Turnbull A. P., Fleming F., Poston D. J. *et al.* (2007) Relationship of perceived adequacy of services, family–professional partnerships, and family quality of life in early childhood service programs. *International Journal of Disability, Development and Education* **54**, 319–38.
- Tang C. C., Huang K., Lin C., Lin J. D., Chen Y. C., Lou S. J. *et al.* (2005) Family quality of life for young children with special needs: the measurement tool development in Taiwan. *Taiwan Research on Disability* **3**, 33–53.
- Trute B. (2003) Grandparents of children with developmental disabilities: intergenerational support and family well-being. *The Journal of Contemporary Human Services* **84**, 119–26.
- Turnbull A. P., Brown I. & Turnbull H. R. (eds) (2004) *Families and People with Mental Retardation and Quality of Life: International Perspectives*. American Association on Mental Retardation, Washington, D.C.
- Turnbull A. P., Turnbull H. R., Erwin E. & Soodak L. (2006) *Families, Professionals, and Exceptionality*, 5th edn. Person Education Inc., Upper Saddle River, NJ, USA.
- Turnbull A. P., Summers J. A., Lee S. & Kyzar K. (2007) Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* **13**, 346–56.
- Underhill A. T., LoBello S. G. & Fine P. R. (2004) Reliability and validity of the Family Satisfaction Scale with survivors of traumatic brain injury. *Journal of Rehabilitation Research and Development* **41**, 603–10.
- Verdugo M. A., Schalock R. L., Keith K. D. & Stancliffe R. J. (2005) Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research* **49**, 707–17.
- Wang M. & Brown R. (2009) Family quality of life: a framework for policy and social service provisions to support families with children with disabilities. *Journal of Family Social Work* **12**, 144–67.

- Wang M., Summers J. A., Littile T., Turnbull A., Poston D. & Mannan H. (2006) Perspectives of fathers and mothers of children in early intervention programs in assessing family quality of life. *Journal of Intellectual Disability Research* **50**, 977–88.
- Wang M., Samuel P., Isaacs B. J., Baum N. & Brown I. (2008) *Examining the factor structure of FQOL survey*. Paper presented at the IASSID Congress, Cape Town, South Africa.
- Warfield M. E., Hauser-Cram P., Krauss M. W., Shonkoff J. P. & Upshur C. C. (2000) The effect of early intervention services in maternal well-being. *Early Education and Development* **11**, 499–517.
- Werner S., Edwards M., Baum N., Brown I., Brown R. I. & Isaacs B. J. (2009) Family quality of life among families with a member who has an intellectual disability: an exploratory examination of key domains and dimensions of the revised FQOL survey. *Journal of Intellectual Disability Research* **53**, 501–11.
- Wertlieb D. (2003) Converging trends in family research and pediatrics: recent finds for the American Academy of Pediatric task force on the family. *Pediatrics* **111**, 1572–8.
- Williams A. R., Piamjariyakul U., William P. D., Bruggman S. K. & Cabanela R. (2006) Validity of the Revised Impact on Family (IOF) scale. *Journal of Pediatrics* **111**, 257–61.
- Zuna N., Selig J. S., Summers J. A. & Turnbull A. P. (2009a) Confirmatory factor analysis of a Family Quality of Life Scale for families of kindergarten children without disabilities. *Journal of Early Intervention* **31**, 111–25.
- Zuna N., Turnbull A. P. & Summers J. A. (2009b) Family quality of life: moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities* **6**, 25–31.
- Zuna N., Summers J. A., Turnbull A. P., Hu X. & Xu S. (2010) Theorizing about family quality of life. In: *Enhancing Quality of Life for People with Intellectual Disabilities: From Theory to Practice* (ed. R. Kober), pp. 241–78. Springer Publishing, Dordrecht, Netherlands.

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## Appendix I

### Twenty-five databases

Article First, BlackWell Synergy, Education Abstracts, ERIC, Expanded Academic, Google Scholar, Health and Wellness Resource Center, Info Trac One-File Plus, JSTOR, Medline Plus, ProQuest Nursing and Allied Health, ProQuest Research Library, PsychINFO, Pub Med, Sage Journals On-Line, Science Direct, Social Service Abstract Social Work Abstracts, Sociological Abstracts, Science Direct, Springer Link, Wiley Interscience Journals, Web of Science, Wilson Web, and Windows Live Academic.

## Appendix 2 Tables

**Table A1** Review of family quality of life (FQOL) instruments in disability field

Instrument	Purpose/theoretical base	Respondent	Domains assessed	Response options/scoring techniques	Number of items/psychometric properties
The Beach Center Family Quality of Life Scale (Beach Center on Disabilities 2006)	To measure family perceptions of satisfaction on different domains of FQOL and to evaluate the family service programmes Not reported	Parents	Five domains: Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, Disability-Related Services	<i>Satisfaction:</i> 1 = very dissatisfied, 3 = neither satisfied nor dissatisfied and 5 = very satisfied <i>Satisfaction</i> means ratings of each domain range from 1 to 5	25 items Satisfaction coefficient alpha = 0.88 Concurrent validity with other scales: Family APGAR and Family Resource Scale
The Family Quality of Life Survey (I. Brown <i>et al.</i> 2006)	To collect data about FQOL of families with one or more members with intellectual disability and to assist families to better understand their unique needs and state of family life Not reported	Parents	Nine domains: Health, Finances, Family Relationships, Support from Other People, Support from Disability-Related Services, Influence of Values, Careers and Planning for Careers, Leisure and Recreation, and Community Interaction	Six core concepts: <i>Importance:</i> 1 = hardly important at all, 3 = somewhat important and 5 = very important <i>Opportunity, Initiative, and Attainment:</i> 1 = hardly any, 3 = some and 5 = a great many <i>Stability:</i> 1 = greatly decline, 3 = stay about the same and 5 = greatly improve <i>Satisfaction:</i> 1 = very dissatisfied, 3 = neither satisfied or dissatisfied and 5 = very satisfied Mean of each domain ranges from 1 to 5	54 items Coefficient alpha = 0.60 to 0.92
Family Quality of Life Questionnaire for Young Children with Special Needs (Tang <i>et al.</i> 2005)	To explore the presumptions of family members on FQOL, to assess outcomes of family service plan and to facilitate family policy making Not reported	Parents, grandparents	Six domains: Family Interaction and Psychological Well-Being, Family Health and Material Well-Being, Community Environment and Safe Well-Being, Family Productivity and Self-Determination, Social Well-Being, and Family Life Routines Well-Being	Four core concepts: <i>Present situation:</i> 1 = very bad, 3 = just OK and 5 = very good <i>Possibility to achieve:</i> 1 = totally unlikely, 3 = likely and 5 = very likely <i>Active efforts made to achieve:</i> 1 = almost none, 3 = some and 5 = a great deal <i>Satisfaction:</i> 1 = dissatisfied, 3 = neither satisfied or dissatisfied and 5 = very satisfied Responses for the 35 items are summed Scores for each sub-scale range from 3 to 45	35 items Factor analysis presents the six factors account for 88.4% of variance Coefficient alpha = 0.97
The Latin American Quality of Life Scale (Aznar & Castañón 2005)	To measure quality of life among Latin American families Topological model of quality of life as a product of three factors: objective/material, subjective/personal, contextual/social	Individual family member	Six domains: Emotional well-being, Personal strength and development (related to self-determination), Roles of cohabitation (related to rights in family/organisational context), Physical/material well-being, Family life, and Social/community relations	Frequency (of indicators that express satisfaction): Always (3), Sometimes (2) and Never (1) Sum scores and sub-scores (for individual analysis) Table of frequencies (for group analysis)	42 items N/A
Quality of Life Questionnaire (Bowman 2001)	To assess quality of life of children with developmental disabilities and their family Individual quality of life	Mothers	Four domains: Developmental Level, Behaviour Problems, Satisfaction/Social Support, and Psychiatric History	<i>Satisfaction:</i> 1 = not at all satisfied, 3 = neutral/unsure and 5 = very satisfied Mean of each sub-scale ranges from 11 to 55	11 items measure FQOL from the total 28 items Test-retest reliability coefficients for Satisfaction/Social Support = 0.85 Coefficient alpha = 0.37 to 0.56

Table A2 Review of family quality of life (FQOL) instruments in healthcare field

Instrument	Purpose/theoretical base	Respondent	Domains assessed	Response options/scoring techniques	Number of items/psychometric properties
The Multidimensional Assessment of Parental Satisfaction for Children with Special Needs (Reys & Perry 1999)	To measure family satisfaction with healthcare providers Not reported	Parents	Five domains: Developmentally appropriate care, Family-centred care, Coordinated care, Technical competence, and Interpersonal competence	5-point anchored response on judging provider: 1 = does not apply or poor, 3 = good and 5 = excellent Percentage of respondents on both satisfaction and dissatisfaction	12 items Internal consistency = 0.87 Coefficient alpha = 0.85 to 0.91
The Revised Impact on Family Scale (Stein & Riessman 1980; Stein & Jessop 2003; Williams <i>et al.</i> 2006)	To assess the impact of childhood illness on family Family adaptation	Parents, mothers, siblings	One robust factor representing the overall family impact	4-point: 1 = strongly disagree and 4 = strongly agree Mean as the main score for analysis, higher score indicates higher burden	15 items Correlation of the previous Impact on Family Scale = 0.97 Coefficient alpha = 0.82 to 0.90
The Family Dermatology Life Quality Index (Basra <i>et al.</i> 2006)	To measure the health-related quality of life of family members of patients with skin disease FQOL framework developed by the Beach Center on Disability	Immediate family members accompanying patients, sons, daughters, spouse, grandparents	Two domains: Psychosocial impact and Physical impact	The degree of the impact of disease on quality of life: 0 = not at all/not relevant, 1 = a little, 2 quite a lot and 3 = very much Total score ranges from 0 to 26	10 items Two factors explain 60% of the common variance Coefficient alpha = 0.88 Test-retest reliability = 0.94
Quality of Life in Life Threatening Illness – Family Carer Version (Cohen <i>et al.</i> 2006)	To measure quality of life of people with terminal cancer and that of their families Not reported	Individual primary family caregivers	Global overall quality of life and seven sub-domains: State of carer, Patient Well-being, Quality of care, Outlook, Environment, Finances, and Relationships	11-point scale: Frequency: 0 = never, 10 = always Bipolar adjective: 0 = not at all, 10 = completely; 0 = extremely poor, 10 = extremely good Identification: 0 = not a problem, 10 = a huge problem; 0 = comfortable, 10 = stressful Satisfaction: 0 = unsatisfactory, 10 = extremely good Total score is the mean of both the sub-scale and single-item scores; the interpretation of differences in scores is rated as very good/good, average, bad/very bad	16 items The seven domains' scores explain 53% of the variance Coefficient alpha = 0.86 Test-retest reliability = 0.77 to 0.80

**Table A3** Review of family quality of life instruments in family field

Instrument	Purpose/theoretical base	Respondent	Domains assessed	Response options/scoring techniques	Number of items/psychometric properties
Family Adaptability and Cohesion Evaluation Scales IV (Olson <i>et al.</i> 2007)/(Lusting & Akey 1999; Warfield <i>et al.</i> 2000)	To assess family cohesion and flexibility The Circumplex Model of Marital and Family Systems	Individual family member, 12-year-olds through adults	Two balanced sub-scales: Balanced Cohesion and Balanced Flexibility Four unbalanced sub-scales: Disengaged and Enmeshed for the Cohesion dimension and Rigid and Chaotic for the Flexibility dimension	Bipolar Likert point, positive numbers are representing the positive directions and degree on the item and vice versa The summed scores are located in graphic representation of the Circumplex Model Formula used: Cohesion = Balanced cohesion + (Disengaged – Enmeshed/4) Flexibility = Balanced flexibility + (Rigid – Chaotic/4)	42 items Coefficient alpha = 0.77 to 0.93 Test-retest reliability coefficient = 0.83 to 0.93 Concurrent validity for three other scales, including the Self-Report Family Inventory, Family Assessment Device and the Family Satisfaction Scale
Family APGAR (Smilkstein 1978)/(Chen & Clark 2007)	To measure satisfaction with family life Family systems theory, stress and coping theory	Individual family member	Five domains: Adaptation, Partnership, Growth, Affection, and Resolve	Frequency 5-point: 1 = never, 3 = some of the time and 5 = always Total score ranges from 0 to 20	5 items Coefficient alpha = 0.86 Test-retest reliability coefficient = 0.83
Family Environment Scale (Moos & Moos 2002)/(Warfield <i>et al.</i> 2000; Lewis <i>et al.</i> 2006)	To assess the social environment properties of all types of families and perceived family support Social-ecological-psychological theory, family systems theory	Individual family members over age 11	Ten sub-scales on three dimensions: Relationships (Cohesion, Expressiveness, Conflict), Personal Growth (Independence, Achievement, Orientation, Intellectual-Cultural Orientation, Active-Recreational Orientation, Moral-Religious Emphasis), and System Maintenance (Organisation, Control, Expressiveness, Conflict)	True-false format The 'true' responses for each sub-scale are summed, then converted to standard scores and presented on a profile form, showing the factors above the normal range. Additional coding system is used	90 items Coefficient alpha = 0.61 to 0.78 Test-retest reliabilities = 0.52 to 0.89 Internal consistency and validity has been established in more than 200 studies, indicating various results based on different family types and family characteristics
Family Satisfaction Scale (Olson & Wilcox 1982)/(Underhill <i>et al.</i> 2004)	To assess the satisfaction of family members in regard to family cohesion, flexibility and communication The Circumplex Model of Marital and Family Systems	Individual family members	Two domains: Family Cohesion and Family Adaptability	5-point Likert format: 1 = dissatisfied, 3 = generally satisfied and 5 = extremely satisfied Scores of each domain are summed, with the total score of sub-scales ranging from 6 to 40	14 items Coefficient alpha = 0.92 Test-retest correlation for the total score = 0.75
Family Assessment Device (Epstein <i>et al.</i> 1983)/(Lusting & Akey 1999; Herring <i>et al.</i> 2006; Chen & Clark 2007)	To assess the family function The McMaster Model of Family Functioning	Individual family members age 12 and older	Seven domains: Problem solving, Communication, Roles, Affective responsiveness, Affective involvement, Behaviour control, and General functioning	4-point Likert Disagree-Agree Format: 1 = strongly agree to 4 = strongly disagree Means of each sub-scale range from 1 (healthy) to 4 (unhealthy)	60 items Coefficient alpha = 0.72 to 0.92 Test-retest reliability coefficients = 0.66 to 0.76 Concurrent validity with other scales
Family Member Well-Being Index (McCubbin & Patterson 1982)/(Nachshen & Mimes 2005)	To measure the current well-being of a family member T-Double ABCX Model of Family Adjustment and Adaptation	Individual family member	Eight domains: Health, Tension, Energy, Cheerfulness, Fear, Anger, Sadness, and General concern	10-point Likert format: 0 = very much so, 10 = not at all Total scores are summed with lower scores indicating family difficult adaptation	8 items Coefficient alpha = 0.86 Its validity has been established at 0.38
Family Assessment Measure (Skinner <i>et al.</i> 1983)/(True 2003)	To be used as a measure of therapy process and outcome, family process studies The Process Model of Family Functioning	Individual family members over 10 to 12 years old	Three scales versions on general studies, dyadic studies, individual family member studies Seven consistent domains: Task Accomplishment, Role Performance, Communication, Affective Expression, Affective Involvement, Control, Values and Norms For general scale, two more domains of Social Desirability and Denial-Defensiveness added	4-point Likert format: 1 = strongly agree and 4 = strongly disagree The sum scores of sub-scales are converted to standard scores, then plotted onto separate profile for each scale	42-50 items Coefficient alpha = 0.65 to 0.95 across sub-scales for parents and children across studies Test-retest correlations = 0.56 to 0.66