

Review

The development of family quality of life concepts and measures

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Abstract

Historically, intervention programmes in intellectual and developmental disabilities have targeted the individual's special needs independent of the family and environmental context. This trend has been changing over the past two decades. This paper presents a literature review on changing trends in family support and the development of family quality of life (FQOL) and intellectual disability from a construct to a theory. The evolution of research in quality of life from the perspective of the individual with the disability to the family is described. A description of the development of FQOL measures is included, specifically an introduction and comparison of the two leading comprehensive initiatives on measuring FQOL – international FQOL project and the FQOL initiative of the Beach Center on Disability, in the USA. This paper provides the conceptual background and context to the other papers presented in this special

issue, which focus on FQOL measurement in specific contexts.

Keywords family quality of life, measurement issues, parents, theory

Overall purpose of family quality of life study

Disability intervention programmes have traditionally targeted the individual's special needs independent of the family and environmental context. This trend has been changing over the past two decades, however, with increasing emphasis on supporting children and adults with intellectual disabilities (ID) in their family homes (Brown *et al.* 2003; Turnbull *et al.* 2004b; Brown 2010). This shifting of focus has resulted in changes to both policy and practice such that the family is now the primary environment of most children and many adults who have ID (Parish *et al.* 2001; Turnbull *et al.* 2001, 2007a).

Families have always been crucial to successful living for children and adults with ID, but recent

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changes in laws, especially in the more affluent countries, have resulted in families becoming more important than ever. In the United States, the Education for All Handicapped Children Act (1975; popularly known as PL 94-142) set a strong example of a philosophical and legal basis for providing education for all children in local schools, thus enabling them to remain living in the family home through their childhood and adolescence. Similar legislation has been enacted in many other countries. At the same time, government policy documents that address service programmes for children and adults with ID have increasingly called for an augmented role for families in providing support for people with disabilities and for helping to make critical decisions about their lives. As a consequence, there has been an increasing reliance on families to act as the main caregivers and decision makers regarding disability supports (Brown *et al.* 2009).

The success of an increased role for families relies on assumptions by policy makers that most families are both able and willing to act as the main caregivers and decision makers, and that family life will be enhanced as a result of their greater involvement. The importance of family capacity that is underscored by emerging evidence-based practice in more affluent countries (Isaacs *et al.* 2007) suggests that family self-sufficiency and capacity for quality family living is enhanced by family skill building and empowerment, and that this appears to be a viable approach to addressing support needs of individuals with disabilities (Dunst 1997; Thompson *et al.* 1997; Bailey *et al.* 1998; Turnbull *et al.* 2004b). Early qualitative data from family support programmes suggest that such a family-centred, strengths-based approach is effective in empowering families of children with disabilities (Llewellyn *et al.* 1999, 2003; Morrissey 2005).

The emerging focus on conceptualising and researching family quality of life (FQOL) addresses, in part, whether or not assumptions that most families are both able and willing to act as the main caregivers and decision makers, over time, are valid. More specifically, FQOL inquiry aims to ascertain the degree to which these assumptions are a reality by describing family life, determining aspects of family life that contribute

to and detract from FQOL and suggesting how aspects of life can be improved to enhance overall FQOL.

Development of family quality of life study

Development of family quality of life from family study and support

The FQOL construct has been conceptualised throughout the world on the thesis that families form the primary structure to the functioning and ongoing stability of societies (Brown & Brown 2003). The family, a universal social institution of humans throughout their evolution, is the fundamental unit of human societies. Its definition and structure are diverse, ranging from two-person bonds to large complex systems. Defining a family is particularly difficult in today's world, where there is broad acceptance of a wide variety of family types and structures. Cultural and ethnic composition of families is becoming increasingly diverse, especially in developed countries with high immigration rates. Structural, cultural and linguistic diversity in families leads to heterogeneous family values, beliefs and practices, all of which are often not adequately addressed by most disability practitioners, scholars and policy makers (Samuel 2007; Yaoying 2007). In view of this, one useful definition, adapted from the definition developed by the Beach Center on Disability (2003), is that a family is those 'people who are closely involved in the day-to-day affairs of the household and support each other on a regular basis; whether related by blood, marriage or by close personal relationship' (Rillotta *et al.* 2011).

According to family systems theory, families are goal-directed, self-correcting, dynamic, interconnected systems that influence and are in turn influenced by their environment and their inherent qualities (Klein & White 1996). Thus, each family member is linked to each other and to his or her environment; what impacts one member of the family impacts the entire family system. Having a family member with a disability is often challenging for each member in the family, and families are not always able to function well as a result. When disability service systems attempt to support families, their role should be to help family systems function

better by focusing on improving the quality of multiple aspects of family life. However, because disability service systems are sometimes more concerned with curtailing expenses, than doing what is necessary to improve quality of family life, their interventions can be ineffective in supporting family units in positive ways.

The FQOL approach is the 'embodiment of a paradigm shift' in disability service provision as it moves from fixing to supporting, from deficits to strengths and from child to family as the focus of support (Turnbull *et al.* 2007a, p. 565). The rationale of the FQOL framework in family support is that 'families that function well support societies, and families with effective QOL are seen as a social resource' (Isaacs *et al.* 2007, p. 178). Families are well supported when their unique strengths are built upon through a strengths-based family-centred model of intervention, rather than focusing on their weaknesses (Bailey *et al.* 1998; Turnbull & Turnbull 2001; Blue-Banning *et al.* 2004; Seligman & Darling 2007). The dynamic relationship between FQOL and family support is well summarised by a recently proposed definition of FQOL theory:

Systems, policies, and programs indirectly impact individual and family-level supports, services, and practices; individual demographics, characteristics, and beliefs and family-unit dynamics and characteristics are direct predictors of FQOL and also interact with individual and family level supports, services, and practices to predict FQOL. Singly or combined, the model predictors result in a FQOL outcome that produces new family strengths, needs, and priorities which re-enter the model as a new input resulting in a continuous feedback loop throughout the life course (Zuna *et al.* 2011).

Development of family quality of life from individual quality of life research

The QOL concept became popular in the early 1990s, but scholars and practitioners in the field of intellectual and developmental disabilities have taken the lead in developing the concept of QOL in a holistic manner (Brown 1999). Several articles and texts have explored the conceptual basis of QOL and the life domains associated with it, such

as physical and material well-being, emotional well-being, social belonging and community living (e.g. Brown *et al.* 2000; Schalock & Verdugo 2002; Brown & Brown 2003; Schalock 2004). Schalock *et al.* (2007) set out useful methods for applying QOL at the systems and organisation levels, and Zuna *et al.* (2011) have embarked upon some useful exploration of QOL as theory. In addition, numerous QOL measures have been developed and validated since 1990, several for individuals with ID (see Australian Centre on Quality of Life 2008 for a current list of available QOL instruments; also see Cummins 1991; Summers *et al.* 2005; Isaacs *et al.* 2007; Lin *et al.* 2009). More recently, the focus of QOL work has moved to its application and specific ways to translate concepts into practice that result in observable improvement (Schalock 2004; Brown & Brown 2005; Brown *et al.* 2009; Verdugo & Schalock 2009; Zuna *et al.* 2009).

Quality of life is a social construction that is conceived as composed of several core concepts, domains and indicators that are shared among people, as well as characteristics and interests that are unique to individuals (Brown & Brown 2003; Schalock *et al.* 2007). The application of these components to measurement and practical support is guided by principles that arose from a 2-year initiative of international QOL experts (Schalock *et al.* 2002). Such principles are important to help focus the ethical development of this relatively new approach to practice in the field of disability (Turnbull *et al.* 1994; Brown *et al.* 2000, 2003; Isaacs *et al.* 2007), especially since – as Brown & Brown (2003) demonstrated – unique ethical dilemmas can result from taking a QOL approach to supporting people with disabilities, as the world view of persons with disabilities and service providers may differ. As a consequence, although one of the basic tenets of QOL is to allow for exercising of personal choice to empower individuals to have control over their lives (Brown & Brown 2009), such choice may not always be perceived by others to be in the best interests of the individual, fit with the priorities of other family members or be consistent with the mandate of service providers. Such differences lead to ethical and professional challenges for those supporting people with disabilities.

Quality of life study leads to a critical appraisal of both disability itself and support to people with

disabilities by assuming that all people, regardless of whether they have a disability, deserve lives of quality, and by exploring the degree to which we have been able to help make this a reality. Such appraisal makes practitioners respond to individual needs in creative ways that directly lead to improved happiness and life conditions, rather than through the traditional models of practice, which focused primarily on addressing care needs. One of numerous examples that have emerged to show the importance of empowerment was that of students in the UK with writing challenges who were given entitlement to grants for assistive technology. After their chosen technical support was introduced, their disability became secondary. Some of those students even started taking pride in their writing challenges after receiving this environmental support (Brown & Brown 2003). The appraisal of disability and disability supports that a QOL approach engenders is useful within all five foundations of practice, namely: assessment, intervention, professional practice, policy and research (Brown & Brown 2003). A QOL approach works to ensure that people with disabilities and their families experience a high level of well-being, despite their limitations or declining abilities. Thus, the focus is to maintain adequate levels of functioning in areas that are important to the individual or the family for as long as possible (Brown & Brown 2003).

Parents and family members have welcomed the focus on individual QOL, but they have often expressed the need for service providers to understand the QOL of the entire family (Renwick *et al.* 1998). In response to this need, FQOL began to emerge as a concept around the turn of the millennium, and measures began to appear shortly afterward (Turnbull *et al.* 2004b; I. Brown *et al.* 2006).

Family quality of life measures

Setting the scene for family quality of life measures

There have been many efforts to assess particular areas of family life, such as family leisure and recreation and the lack of spontaneity in such pursuits (Mactavish & Schleien 2004; Songjae *et al.* 2004); stress, burden and coping of family caregivers (Floyd & Gallagher 1997; Cummins 2001; Hastings

2002; Emerson 2003; Glidden *et al.* 2006; Skok *et al.* 2006; Lloyd & Hastings 2009; Phelps *et al.* 2009; Hill & Rose 2009); and the impact on siblings (Seltzer *et al.* 1997; Greenberg *et al.* 1999; Strohm 2002; Cuskelly & Gunn 2006; Giallo & Gavidia-Payne 2006; Ross & Cuskelly 2006). Still, there have been few attempts to measure the life of the family in a comprehensive holistic way, perhaps because its inherent nature is complex.

Because of this complexity, FQOL researchers followed the example of individual QOL study and began by thinking of FQOL as a multidimensional social construct. Constructing FQOL in this way made the various dynamics of family life easier to understand and measure. The thinking was that each dimension could be measured independently, using indicators that are common to families. The data from the dimensions could then be put together to describe FQOL as a whole. Five characteristics of measuring QOL that were suggested by Verdugo *et al.* (2005b, p. 707) appear also to be highly relevant to FQOL measurement:

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

Family quality of life measures developed

There have been only a few attempts at systematic empirical measurement of FQOL (for a comprehensive list on FQOL measurement efforts, see Zuna *et al.* 2011). The earliest systematic assessment of FQOL was based on the work of Olson & Barnes (1982). The aim of their work was to use QOL as a subjective measure to assess the sense of fit between the family of typically developing adolescents and their environments. This tool measures life satisfaction of parents in 12 domains and of adolescent in

11 life domains. There is no evidence of further use of this measure among families of persons with intellectual and developmental disabilities (Summers *et al.* 2005). FQOL in the intellectual/developmental disability context was initially measured by scholars using specific questions to rate FQOL as an outcome within broader evaluation tools (Feldman & Werner 2002; Dunst *et al.* 2006), interviews (Bowman 2001; Abbott *et al.* 2005) or using satisfaction scales (Zabriskie & McCormick 2003; Hornstein & McWilliam 2007). A comprehensive FQOL tool was developed specifically for Latin American families of persons with ID through a three-phase research study (Aznar & Castanon 2005). It consisted of 42 items organised into six family domains: emotional well-being, personal strength and development, cohabitation rules, physical/material well-being, family life, and interpersonal and community relations.

Currently, there are only two major initiatives to systematically measure FQOL perhaps because the FQOL construct is still in its early stages of growth. The *Beach Center Family Quality of Life Scale* (Beach Center FQOL Scale; Beach Center on Disability 2005), developed by a team of researchers at the Beach Center for Disability at the University of Kansas, KS, USA, and the *Family Quality of Life Survey (FQOLS-2006)*, developed by an international team of researchers, are being increasingly used with families of persons with intellectual and developmental disabilities. These measures are described in detail below, and are featured in subsequent articles of this issue.

Beach Center Family Quality of Life Scale

The Beach Center on Disability at the University of Kansas, KS, USA developed a conceptualisation of FQOL and a valid method for measuring it. They also developed a brief FQOL scale through several phases of qualitative and quantitative research on FQOL conceptualisation and measurement (Park *et al.* 2003; Poston *et al.* 2003; Turnbull *et al.* 2004b; Summers *et al.* 2005; Hoffman *et al.* 2006).

The preliminary version of the *Beach Center FQOL Scale*, which was developed following extensive qualitative research, had 10 domains (family interaction, parenting, daily life, financial well-

being, emotional well-being, social well-being, health, physical environment, advocacy and productivity) and 112 items. It was field-tested on a representative group ($n = 1197$) across 13 geographically representative states in the USA, which resulted in a five-domain 41-item survey (Park *et al.* 2003). After further field tests, it was reduced to a brief and concise *Beach Center FQOL Scale, version 2003* consisting an 11-page instrument that had three sections: demographic questions about the family and the family member with the disability, Importance and Satisfaction ratings of 25 items grouped into five FQOL domains (Family interaction, Parenting, Emotional well-being, Physical and material well-being), and disability-related support (Park *et al.* 2003). The scale is reported to have satisfactory psychometric properties, that is, test-retest reliability, and convergent and construct validity (Summers *et al.* 2005; Hoffman *et al.* 2006). Importance ratings were found to be high for most items on the survey and, although this supports the validity of the items, data from the Importance measures were not very useful in FQOL evaluation (e.g. Cummins 2005). For this reason, the 2005 version of the *Beach Center FQOL Scale* does not use Importance ratings, especially when the scale is used as an outcome measure of FQOL. Nevertheless, scholars are still using it when its psychometric properties are being evaluated in various contexts (e.g. Zuna *et al.* 2009). The most current version of the *Beach Center FQOL Scale* (Beach Center on Disability 2005) does not include importance ratings or demographic questions, making it much shorter, and allowing researchers to include this tool along with other tools for evaluation in a project.

The 2003 version of the *Beach Center FQOL Scale* was translated into Spanish and validated for use among European Spanish speakers (Verdugo *et al.* 2005a). This Spanish version of the *Beach Center FQOL Scale* is available for use among Mexican Spanish speakers, although it has not been validated in a large study to date (J. A. Summers 2011, personal communication). Numerous training sessions, conference presentations and academic publications have resulted from this very considerable work (e.g. Park *et al.* 2002, 2003; Poston *et al.* 2003; Poston & Turnbull 2004; Wang *et al.* 2004; Summers *et al.* 2005; Turnbull *et al.* 2007b).

Family Quality of Life Survey

An international FQOL project evolved out of individual QOL research in the late 1990s. Its first measure, the *Family Quality of Life Survey 2000* (*FQOLS-2000*; Brown *et al.* 2000), was developed by a team of QOL experts from Australia, Canada and Israel (I. Brown *et al.* 2006; Isaacs *et al.* 2007) using data from volunteer parents from service organisations with which they and colleagues in other countries were affiliated. This project collected FQOL data in several countries and produced numerous training sessions, professional and academic presentations, and academic publications (e.g. Brown *et al.* 2003; R. I. Brown *et al.* 2006; Isaacs *et al.* 2007; Brown 2010). The Beach Center on Disability initiative and this international project also collaborated on producing the first – and, to date, the only – book that focused specifically on FQOL (Turnbull *et al.* 2004a).

The international team of researchers amended its survey, and the resulting *Family Quality of Life Survey 2006* (*FQOLS-2006*; I. Brown *et al.* 2006) has been translated into at least 20 languages. The evolution of the survey is described in detail by Isaacs *et al.* (2007). The main changes from *FQOLS-2000* to *FQOLS-2006* are the addition of the measurement dimension of Importance, change in name of a few domains, standardising the Likert scales and slight changes in wordings of some questions, for the purpose of clarification. To date, it has been used, or is currently in use, in FQOL projects in more than 25 countries. Some initial cross-country comparisons have been made (Brown 2010) and others are underway (see other articles in this issue for several country-specific FQOL reports). The basic QOL principles inherent in the *FQOLS-2006* are (Isaacs *et al.* 2007, p. 179):

- 1 FQOL is multidimensional and influenced by many factors.
- 2 FQOL is comprised of generally the same dimensions for all individuals or groups, but that some aspects may hold more importance than others for some individuals or groups.
- 3 FQOL includes both subjective and objective elements.
- 4 FQOL is best studied using qualitative and quantitative methodology.

5 FQOL is studied for the specific purpose of understanding and improving life of individuals with disabilities and their families.

The *FQOLS-2006* is designed to assess the multi-dimensional construct of FQOL using nine domains of family life: Health of the family, Financial well-being, Family relationships, Support from others, Support from disability services, Influence of values, Careers and preparing for careers, Leisure and Community involvement. Within each of these domains, six dimensions are measured on a five-point Likert-type scale: Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction. Attainment and Satisfaction are considered to be the two outcome measures, while Importance, Opportunities, Initiative and Stability are considered to be explanatory measures.

The *FQOLS-2006* is a comprehensive instrument for assessing FQOL, collecting both quantitative and qualitative data. The survey is currently available in two versions: Main caregivers of people with intellectual or developmental disabilities (*FQOLS-2006, ID/DD version*) and General version (*FQOLS-2006, General version*), and can be downloaded for free (<http://www.surreyplace.on.ca/Education-and-Research/research-and-evaluation/Pages/International-Family-Quality-of-LifeProject.aspx>). The General version was developed for use with families of persons without any disabilities, and thus is useful for control groups or for studies of families without any persons with disabilities. The *FQOLS-2006, ID/DD version* was developed for data collection from the main caregivers of persons with ID.

Both versions of the survey have 11 sections: an introduction; nine parts, one on each of the nine FQOL domains; and a final short section on overall FQOL. The introductory section of the *FQOLS-2006, ID/DD* gathers demographic information about the family and the family member(s) with the disability. The survey allows for collection of data from up to three persons with disabilities within one family. The *FQOLS-2006, General version* uses only nine questions to gather demographic information about the family of the respondent, and asks if any person in the family has any special needs. Both versions have nine sections on FQOL domains and are further divided into Section A (descriptive questions on each domain) and Section B (ratings of the six dimensions referred to above). There

are fewer items in Section A of the *FQOLS-2006, General version* when compared to the *ID/DD version* because all the items relating directly to disability are not included. Section B in both versions of the survey consists of six different questions to measure the six dimensions (Importance, Opportunity, Initiative, Stability, Attainment and Satisfaction) of FQOL in each of the nine life domains. Thus, there are 54 items in Section B.

The order of presentation (descriptive items in Section A, followed by the items to be rated in Section B) was strategically designed to help the respondent think through the issues and challenges faced by the family in each life domain before completing the six-dimension ratings.

In a short version of the survey, the Section A questions are not included but rather respondents are directly presented the Section B questions. This version can be beneficial to researchers who are not interested in all the demographic and service details gathered by the full survey, and who wish to collect FQOL ratings in a less time-consuming manner. The respondents' ratings of each domain might differ if they had a chance to consider aspects of it as they do by responding to the descriptive questions of Section A, and this needs to be explored in future research. Although all questions on dimension ratings are close-ended and worded carefully to test the psychometrics of the tool, there are open questions included as well in order to help explain the ratings provided.

Comparing the two major family quality of life initiatives

There are many similarities and differences between the two FQOL measurement initiatives, some of which will be discussed briefly in this section. The similarities begin with the underlying FQOL theoretical framework that recognises the family environment of the persons with the disability. Both teams of scholars recognise that the experiences of each family and its members are unique and cannot fully be represented by scale scores. Yet, given the increasing need for accountability in service programmes for the purposes of quality assurance and fiscal support, such quantitative measurement efforts are invaluable.

Development and use of the family quality of life instruments

The *FQOLS-2006* was developed to be an international tool, while the *Beach Center FQOL Scale* was developed primarily for young US families of children with disabilities. The *Beach Center FQOL Scale* is increasingly being adapted for use in other countries such as Spain, Australia and China (e.g. Wang *et al.* 2007; Cordoba-Andrade *et al.* 2008; Davis & Gavidia-Payne 2009) and in other contexts, such as with typically developing children (Zuna *et al.* 2009) and children with other disabilities (Jackson *et al.* 2010; Kyzar 2010). The *FQOLS-2006*, in addition to its global focus, is based on a lifespan approach and therefore can be used by families of children, youth, adults and seniors with and without disabilities. Although some of the language in the survey, especially in the introductory section, is specific to intellectual/developmental disabilities, it can be adapted for use with other disabilities acquired later in life. For example, the *FQOLS-2006, General version* has been used with families of persons with acquired brain injury (A. Ranjan 2010, unpublished report), and the *FQOLS-2006, ID/DD version* has been used with families of ageing adults with ID (Jokinen & Brown 2005).

Both of these instruments can be used as outcome measures to evaluate the degree to which policies and supports to families are being effectively applied. The *Beach Center FQOL Scale* has been used to evaluate the supports on families, such as the impact of positive behaviour supports (Smith-Bird & Turnbull 2005), augmentative and alternative communication strategies (Saito & Turnbull 2007), the Medicaid waiver system in one state in USA (Eskow *et al.* 2011) and the impact of professional support for young families in Australia (Davis & Gavidia-Payne 2009). The *FQOLS-2006* has been piloted for use longitudinally as an outcome measure to evaluate the efficacy of an empowerment model of family support for urban, low-income, minority families in the USA (Samuel *et al.* 2010).

Domains of the instruments

The *FQOLS-2006* is composed of nine domains while the *Beach Center FQOL Scale* consists of five domains (see Table 1). Both instruments can collect

Table 1 Comparing the domains and number of questions in the family quality of life (FQOL) instruments

Domains	Number of descriptive questions	Number of objective questions (psychometric measures)
FQOLS-2006 domains*		
1. Health of the family	3	6
2. Financial well-being	6	6
3. Family relationships	3	6
4. Support from others	5	6
5. Support from disability-related services	3	6
6. Influence of values	5	6
7. Careers and preparing for careers	6	6
8. Leisure and recreation	3	6
9. Community interaction	4	6
Beach Center FQOL Scale domains		
1. Physical and material well-being	0	5
2. Emotional well-being	0	4
3. Family interaction	0	6
4. Parenting	0	6
5. Disability-related support	0	4

* There are 13 other questions in the introductory section, and seven in the final section on global FQOL (two questions on global FQOL are psychometrically testable).

FQOLS-2006, Family Quality of Life Survey-2006.

qualitative data, depending on the specific method of administration (self-administration, interview, etc.) and the particular version of the tool that is used. Apart from the differences in names of domains, the construction of each domain also varies in both its quantity of items, content and response categories. There are four to six questions in each of the domains of the *Beach Center FQOL Scale*, while there are three to six questions in Section A and eight questions in Section B of each of the *FQOLS-2006* domains. This is better illustrated in Table 2, by a close examination of the items and response categories in one of the most conceptually related domains in both instruments.

The domains in both instruments are similar in several ways, although the domains of Parenting and Emotional well-being seem to be brought to the forefront by the *Beach Center FQOL Scale*. The domains of Family life and Support from disability-related services are seen in both instruments, although the content is different due to the number of dimensions or measurement indicators and the structure of the instruments. The *FQOLS-2006* has a much broader focus and includes the domains Influ-

ence of values, Careers and preparing for careers, Community interaction and Leisure, which are not captured in depth by the *Beach Center FQOL Scale*. The *Beach Center Family Community Integration Survey* (FCIS; Beach Center on Disability 2006), consisting of 27 items to evaluate the family's involvement in community activities and the barriers to involvement, was developed as a companion tool to the *Beach Center FQOL Scale*. The FCIS measures the overall satisfaction with the family's community inclusion and it has been reported to be valid and reliable based on field-testing with 324 participants from nine states in the USA (Beach Center on Disability 2006). The broad focus of the *FQOLS-2006* might be narrowed with ongoing psychometric evaluations of the tool and also when the instrument is tailored to match the needs of specific projects or specific population groups.

The domain of Parenting, unique to the *Beach Center FQOL Scale*, contains six items related to teaching children independence, social interaction, academics, decisions making, and time spent caring for the child and knowing the child's peers and teachers. On a similar note, the domain of Influence

Table 2 Comparison of items and response categories in formal supports domain

	Beach Center FQOL Scale	FQOLS-2006*
1.	My family member with special needs has support to make progress at school or work place. <i>Very satisfied, Satisfied, Neither satisfied or dissatisfied, Dissatisfied, Very dissatisfied</i>	Indicate which of these services, if any, are available in your area (check ✓ as many as apply). <i>A list of 27 services or write in any 'other' services</i>
2.	My family member with special needs has support to make progress at home. <i>Very satisfied, Satisfied, Neither satisfied or dissatisfied, Dissatisfied, Very dissatisfied</i>	Which of these services have you or any of your family members used (check ✓ as many as apply)? <i>A list of 27 services or write in any 'other' services</i>
3.	My family member with special needs has support to make friends. <i>Very satisfied, Satisfied, Neither satisfied or dissatisfied, Dissatisfied, Very dissatisfied</i>	a. If there are disability-related services you need that you are not currently getting, <i>please list them.</i> b. Why are you not receiving the disability-related services you need? <i>Choose from a list of nine different barriers/write in any 'other' barrier</i>
4.	My family has a good relationship with the service providers who work with our family member with a disability. <i>Very satisfied, Satisfied, Neither satisfied or dissatisfied, Dissatisfied, Very dissatisfied</i>	How important to your family quality of life is support from disability-related services? <i>Very important, Quite important, Somewhat important, A little important, Hardly important</i>
5.		Are there opportunities in your area to receive the intellectual disability-related services your family needs? <i>A great many, Many, Some, A few, Hardly at all</i>
6.		Do members of your family make efforts to obtain the disability-related services they need? <i>A great deal, Quite a bit, Some, A little, Hardly at all</i>
7.		To what degree are your family needs related to the family member(s) with an intellectual disability being met by the services in your area? <i>A great deal, Quite a bit, Some, A little, Hardly at all</i>
8.	–	In the near future, is it likely that the support your family receives from disability-related services will . . . <i>Greatly Improve, Improve, Stay about the same, Decline or Greatly decline?</i>
9.		If improve or decline, why? <i>Space to write comments</i>
10.	–	All things considered, how satisfied are you with the disability-related services your family receives? <i>Very satisfied, Satisfied, Neither satisfied or dissatisfied, Dissatisfied, Very dissatisfied</i>
11.		Please provide any additional information or explanation that you would like.

* Short version of the FQOLS-2006, ID/DD version does not contain questions 1–3.

Beach Center FQOL Scale, Beach Center Family Quality of Life Scale; FQOLS-2006, Family Quality of Life Survey-2006; ID/DD version, Family Quality of Life Survey-2006: Main caregivers of people with intellectual or developmental disabilities version.

of values (personal, religious, cultural or spiritual) seems unique to the FQOLS-2006. The content of the four items in the Beach Center FQOL domain of Emotional well-being seem to be captured in part by some of the questions in the FQOLS-2006

domain of Support from others. Although there is no direct question addressing the support a family has for relieving stress in Part 6 of the FQOLS-2006, there are questions on the quality and quantity of support that a family receives from relatives,

extended family, friends and others in Section A and objective ratings of satisfaction with this domain in Section B. The *Beach Center FQOL Scale* item associated with time available to pursue one's own interests might be somewhat captured in part by some of the *FQOLS-2006* questions in the domains on leisure and recreation and community participation, although only future studies on concurrent validity of the measures will validate these possible convergences.

The five items in the *Beach Center FQOL* domain of Physical and material well-being includes a question each on satisfaction with transportation, health care, dental care, financial well-being and community safety. One could argue that three of the *FQOLS-2006* domains (Health of the family, Financial well-being and Community interaction) addresses four of these questions. The question on transportation is addressed by the Section A questions in two *FQOLS-2006* domains (Health of the family and Support from disability-related services). Rillotta *et al.* (2011) reported that the direct assessment of transportation issues and its impact on FQOL in the *Beach Center FQOL Scale* was more beneficial than when it was indirectly assessed in the *FQOLS-2006* as a barrier to accessing health care and service support. Australian families who were interviewed using the *Beach Center FQOL Scale* were more likely to discuss issues such as the importance of having a family car to access appointments than they were when interviewed with the *FQOLS-2006*.

Dimensions of the instruments

As noted, the *FQOLS-2006* uses six different measurement indicators (Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction), which provide comprehensive measurement information, but may be somewhat cumbersome to use because of the repetitive nature of asking all of these indicators in each of the domains.

The *Beach Center FQOL Scale* (Beach Center on Disability 2005) uses only the one measurement indicator – satisfaction, making it a sleeker measure, but providing less measurement information. The *FQOLS-2006* also consists of many descriptive questions (Section A questions of each of the nine domains in Parts 2–9), while the *Beach Center FQOL*

Scale (Beach Center on Disability 2005) does not include any descriptive questions. Importance ratings are currently not being used due to the lack of variance in responses after repeated use of the tool (Hoffman *et al.* 2006). The international FQOL project team is also starting to recognise a similar trend in Importance ratings based on preliminary results from confirmatory factor analysis (Issacs *et al.* 2011). However, further studies involving larger sample sizes are essential before any conclusions can be made on the utility of Importance ratings in aggregate FQOL evaluations. The Importance ratings of family domains, however, cannot be ignored at the individual level. For example, it is essential to know the level of importance that a family attributes to the various domains when planning service provision, or to analyse the level of attainment and satisfaction in a particular life domain of a particular family. Asking respondents to rank the domains by perceived importance to overall FQOL can be useful to practitioners who use the *FQOLS-2006* as an evaluation tool for planning and implementing a family support project.

Global measure of family quality of life

Another major difference between the two tools is the inclusion of an overall assessment of FQOL towards the end of the *FQOLS-2006* after measuring the QOL in the nine domains using six different measurement indicators. Here, two objective questions are used to quantitatively measure the overall rating of FQOL and overall satisfaction with *FQOL* (on a five-point Likert scale), while overall FQOL in the *Beach Center FQOL Scale* is computed from the mean ratings of the 25 items. Studies show that global FQOL ratings are only moderately correlated to the mean Attainment and Satisfaction ratings across the nine domains (Werner *et al.* 2009). This suggests that global measures of FQOL may be beneficial, as they appear to be distinct from the summary-computed scores of FQOL – mean Attainment and Satisfaction in each domain.

Concurrent validity

Two independent studies on concurrent validity have been completed where both of

these instruments have been used on the same sample of people. These studies describe the particular features of the surveys that are unique and those that are shared, and allow for refinement of current FQOL measures or development of new ones. Fifteen participants completed the *FQOLS-2006* and the *Beach Center FQOL Scale version 2003* in Australia (Rillotta *et al.* 2011) and 42 participants completed the *FQOLS-2006* and the *Beach Center FQOL Scale version 2005* in the USA (P. Samuel 2010, unpublished report). Rillotta *et al.* (2011) correlated Satisfaction and Importance ratings of similar concepts in both instruments and found strong correlations between Satisfaction ratings of Health, Finances and Leisure, and moderate correlations between Importance ratings of Finances and Leisure. Samuel (2010) examined concurrent validity by examining the Satisfaction scores in each *FQOLS-2006* domain with the conceptually related Beach Center FQOL domains and found that three of the *FQOLS-2006* domains (Financial well-being, Careers and preparing for careers and Community interaction) were not significantly correlated with any of the *Beach Center FQOL Scale's* domain means. The *Beach Center FQOL* domain of disability support was moderately correlated with the *FQOLS-2006* domains of Support from disability-related services, Support from others, Health of the family and Leisure. Many more associations were found between conceptually related items in both FQOL instruments when examined item by item. It was also found that the domain level outcomes of the *FQOLS-2006* domains of Leisure and Community interaction were correlated with Beach Center FCIS satisfaction with doing things in the community and sense of belonging to the community.

Although the *Beach Center FQOL Scale* is brief and easy to use, it is not well suited for planning and evaluating comprehensive family support projects that include diverse needs of typically underserved families, many of whom live at or below the poverty line and belong to ethnic or racial minority groups. Some of these needs include assistance with maintaining parental rights, identifying family strengths, access to health care, education, employment, housing, respite and community supports in the process of de-institutionalisation (Samuel 2007). Evaluating six dimensions in each of the familial domains of the *FQOLS-2006* is

clearly more useful in supporting and empowering such families, as illustrated in a pilot study with underserved families in the Midwest of the USA (Samuel *et al.* 2010). The *Beach Center FQOL Scale* is useful, however, for evaluating projects that address needs of parents raising young children with various disabilities within their homes. The brevity of the *Beach Center FQOL Scale* is an advantage for project evaluators and service providers who want succinct and quick information on families of persons with disabilities. Such short tools are invaluable to begin the process of measuring family-centred outcomes of formal support programmes directed at the person with the disability or any member of the family of the person with the disability. Nevertheless, in order to truly understand a complex social construct like FQOL, the importance of a multidimensional framework incorporating both qualitative and quantitative elements is essential. Rillotta *et al.* (2011) reported that for both instruments, the qualitative data were considered to be very helpful in explaining and expanding the meaning of the quantitative data. However, further research is required to compare the two measures with a larger sample of participants in different countries, and it is necessary to evaluate the practical usefulness of both surveys, since to date the specific application of FQOL research data to practice has not been explored in depth.

Discussion

This special issue on FQOL research is a valuable step forward in recognising the central role of the family in the lives of persons with disabilities. Universally, families have always found ways to care for persons with disabilities, although the literature appears to be dominated by studies highlighting the negative aspects of caregiving (e.g. Şenel & Akkök 1995; Datta *et al.* 2002; Webster *et al.* 2008). In fact, much of the research on families in general has also focused on dysfunctions of the family unit. According to DeFrain (1999, p. 6), most 20th century researchers have been asking 'Why do families fail?' and therefore have been finding many family problems. Alternatively, he argues that when we start asking 'How do families succeed?' we are more likely to identify strengths in a family, which in turn

can lead to the foundation for continued growth and positive change in a family and a society (p. 13).

In the context of disability research, the family was 'invisible' as a unit of scientific study until about 1940 (Blacher & Hatton 2007, p. 532). Much of the early work was focused on studying the impact of a child's ID on the functioning of the family unit (Faber 1959; Risdal & Singer 2004). Consequently, institutionalisation, later termed as *parentectomy* by some, was considered the best option for the child with the ID (Blacher & Hatton 2007, p. 532). The person with the disability and the family were viewed here as entities that need to be 'fixed' under the dominant medical model of disability intervention. However, with increasing life expectancy of persons with disabilities, rising costs of maintaining institutions, recognition of civil rights of persons with disabilities and the gradual change in the disability paradigm from 'fixing the individual to fixing the environment' (Turnbull *et al.* 2004b, p. 59), the family once again has been ushered to the forefront of caregiving. This is especially true in more affluent countries where recent changes in laws promoting community living have forced families to become decision makers regarding disability supports and navigators of a complex service systems (Brown & Brown 2003).

The systematic initiatives of measuring the social construct of FQOL presented in this issue provide a holistic view of the family, supplementing the common descriptions of families in the literature that describe positive–negative aspects of caregiving, coping strategies and strengths–deficits of families. Studies on development and application of FQOL will offer a positive and comprehensive framework for assessing families of persons with disabilities. The four main goals of all systematic FQOL initiatives (Samuel 2007), and thus those included in this issue, include:

- 1 provide empirical information on the FQOL of families with persons with intellectual or developmental disabilities in various countries to researchers, practitioners and policy makers;
- 2 inform disability practitioners on the plausibility of using an FQOL instrument to plan and implement family-centred intervention plans, and also as an evaluation tool to measure the

effectiveness of various family support efforts (Brown *et al.* 2007);

3 stimulate researchers to replicate studies with families of persons with intellectual or developmental disabilities in other geographical locations and conduct larger-scale studies to continue the validation of the *FQOLS-2006* and *Beach Center FQOL Scale*; and

4 challenge policy makers to evaluate service provision models and legislations for persons with intellectual or developmental disabilities in light of the FQOL approach and use this to influence decisions about future policies.

References

- Abbott D., Watson D. & Townsley R. (2005) The proof of the pudding: what difference does multi-agency working make to families with disabled children with complex health care needs? *Child & Family Social Work* **10**, 229–38.
- Australian Centre on Quality of Life (2008) Instruments. Available at: <http://www.deakin.edu.au/research/acqol/index.php> (retrieved 27 May 2011).
- Aznar A. S. & Castanon 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., Drakes L. A., Hevveler 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.
- Beach Center on Disability (2003) *The Beach Center Family Quality of Life Scale [Survey]*. Beach Center, The University of Kansas, Lawrence, KS, in partnership with families, service providers and researchers.
- Beach Center on Disability (2005) *The Beach Center Family Quality of Life Scale*. Beach Center, The University of Kansas, Lawrence, KS, in partnership with families, service providers and researchers.
- Beach Center on Disability (2006) *Kansas Kindergarten Survey: Family Community Participation [FCIS]*. Beach Center, The University of Kansas, Lawrence, KS, in partnership with families, service providers and researchers.
- Blacher J. & Hatton C. (2007) Families in context: influences on coping. In: *Handbook of Developmental Disabilities* (eds S. L. Odom, R. H. Horner, M. E. Snell & J. Blacher), pp. 531–51. The Guilford Press, New York.
- Blue-Banning M., Summers J. A., Franklan H. C., Nelson L. L. & Beegle G. (2004) Dimensions of family and

- professional partnerships: constructive guidelines for collaboration. *Exceptional Children* **70**, 167–84.
- Bowman R. A. (2001) *Quality of life assessment for young children with developmental disabilities and their families; Development of a quality of life questionnaire*, Ph.D. Dissertation. West Virginia University, WV. Retrieved 22 September 2011, from Dissertations & Theses: Full Text. (Publication No. AAT 3022039).
- Brown I. (1999) Embracing quality of life in times of spending restraint. *Journal of Intellectual & Developmental Disability* **24**, 299–308.
- Brown I. (2010) Family quality of life: a comparison of trends in eight countries. In: *Contemporary Issues in Intellectual Disabilities* (ed. V. P. Prasher), pp. 255–64. Nova Publishers, New York.
- Brown I. & Brown R. (2003) *Quality of Life and Disability: An Approach for Community Practitioners*. Jessica Kingsley Publishers, London.
- Brown I. & Brown R. I. (2009) Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* **6**, 11–18.
- Brown I., Neikrug S. & Brown R. I. (2000) *Family Quality of Life Survey*. Faculty of Social Work, University of Toronto, Toronto.
- Brown I., Anand S., Fung W. L. A., Isaacs B. & Baum N. (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: Main Caregivers of People with Intellectual Disabilities*. Surrey Place Centre, Toronto.
- Brown I., Galambos D., Poston D. & Turnbull A. (2007) Person centered and family centered support. In: *A Comprehensive Guide to Intellectual and Developmental Disabilities* (eds I. Brown & M. Percy), pp. 351–62. Paul H. Brookes Publishing Co., Baltimore, MD.
- Brown R. I. & Brown I. (2005) The application of quality of life. *Journal of Intellectual Disability Research* **49**, 718–27.
- Brown R. I., 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., Schalock R. L. & Brown I. (2009) Quality of life: its application to persons with intellectual disabilities and their families – introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities* **6**, 2–6.
- Cordoba-Andrade L., Gomez-Benito J. & Verdugo-Alonso M. A. (2008) Family quality of life of people with a disability: a comparative analysis. *Universitas Psychologica* **7**, 369–83.
- Cummins R. A. (1991) The Comprehensive Quality of Life Scale – Intellectual Disability: an initial report. *Australia & New Zealand Journal of Developmental Disabilities* **17**, 259–64.
- Cummins R. A. (2001) The subjective well-being of people caring for a family member with a severe disability at home: a review. *Journal of Intellectual & Developmental Disability* **26**, 83–100.
- Cummins R. A. (2005) Issues in the systematic assessment of quality of life. In: *Assessing Adults with Intellectual Disabilities: A Service Provider's Guide* (eds J. Hogg & A. Langa), pp. 9–22. BPS Blackwell, Maiden, MA.
- Cuskelly M. & Gunn P. (2006) Adjustment of children who have a sibling with Down syndrome: perspectives of mothers, fathers and children. *Journal of Intellectual Disability Research* **50**, 917–25.
- Datta S. S., Russell P. S. S. & Gopalakrishna S. C. (2002) Burden among the caregivers of children with intellectual disability: associations and risk factors. *Journal of Intellectual Disabilities* **6**, 337–50. doi: 10.1177/146900470200600401.
- Davis K. & Gavidia-Payne S. (2009) The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual & Developmental Disability* **34**, 153–62.
- DeFraim J. (1999) Strong families. *Family Matters* **53**, 6–13.
- Dunst C., Trivette C., Hamby D. & Bruder M. (2006) Influences of contrasting natural learning environment experiences on child, parent and family well-being. *Journal of Developmental and Physical Disabilities* **18**, 235–50.
- Dunst C. J. (1997) Conceptual and empirical foundations of family-centered practice. In: *Integrated Services for Children and Families: Opportunities for Psychological Practice* (eds R. Illback, C. Cobb & H. Joseph Jr), pp. 75–91. American Psychological Association, Washington, DC.
- Education for All Handicapped Children Act of 1975 (1975) PL 94-142, 20 U.S.C. §§ 1400 *et seq.*
- Emerson E. (2003) Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research* **47**, 385–99.
- Eskow K. G., Summers J. A. & Pineles L. (2011) Exploring effect of autism waiver services on family outcomes. *Journal of Policy and Practice in Intellectual Disabilities* **8**, 28–35.
- Faber B. (1959) Effects of a severely mentally retarded child on family integration. *Monographs of the Society for Research in Child Development* **24**, 1–112.
- Feldman M. A. & Werner S. E. (2002) Collateral effects of behavioral parent training on families of children with developmental disabilities and behavior disorders. *Behavioral Interventions* **17**, 75–83.

- Floyd F. J. & Gallagher E. M. (1997) Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations* **46**, 359–71.
- Giallo R. & Gavidia-Payne S. (2006) Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research* **50**, 937–48.
- Glidden L. M., Billings F. J. & Jobe B. M. (2006) Personality, coping style and well-being of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research* **50**, 949–62.
- Greenberg J. S., Seltzer M. M., Orsmond G. I. & Krauss M. W. (1999) Siblings of adults with mental illness or mental retardation: current involvement and expectation of future caregiving. *Psychiatric Services* **50**, 1214–19.
- Hastings R. P. (2002) Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual & Developmental Disability* **27**, 149–60.
- Hill C. & Rose J. (2009) Parenting stress in mothers of adults with an intellectual disability: parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research* **53**, 969–80.
- 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.
- Hornstein S. & McWilliam R. A. (2007) *Measuring family quality of life in families of children with autism spectrum disorders* (Abstract). Paper presented at the 2007 Annual Conference of the Division for Early Childhood. Available at: <http://www.dec-sped.org/pdf/annualconference/FAM1177%20Poster%20S27%20Measuring%20Family%20Quality%20of%20Life.pdf> (retrieved 15 December 2007).
- Isaacs B., Wang M., Samuel P. S., Rillotta F., Ajuwon P., Baum N. *et al.* (2011) Testing the factor structure of the Family Quality of Life Survey-2006. *Journal of Intellectual Disability Research*. DOI: 10.1111/j.1365-2788.2011.01392.x.
- Isaacs B. J., Brown I., Brown R. I., Baum N. T., Myerscough T. *et al.* (2007) Development of a Family Quality of Life Survey. *Journal of Policy and Practice in Intellectual Disabilities* **4**, 177–85.
- Jackson C. W., Wegner J. R. & Turnbull A. P. (2010) Family quality of life following identification of deafness. *Language, Speech, and Hearing Services in Schools* **41**, 194–205. doi: 10.1044/0161-1461(2009/07-0093).
- Jokinen N. S. & Brown R. I. (2005) Family quality of life from the perspective of older parents. *Journal of Intellectual Disability Research* **49**, 789–93.
- Klein D. M. & White J. M. (1996) *Family Theories: An Introduction*. Sage Publications, Inc., Thousand Oaks, CA.
- Kyzar K. (2010) *The relationship of perceptions of service and support adequacy to family quality of life for families of children with deaf-blindness*. Doctoral dissertation, University of Kansas.
- Lin J.-D., Hu J., Yen C.-F., Hsu S.-W., Lin L.-P., Loh C.-H. *et al.* (2009) Quality of life in caregivers of children and adolescents with intellectual disabilities: use of WHOQOL-BREF survey. *Research in Developmental Disabilities* **30**, 1448–58.
- Llewellyn G., Dunn P., Fante M., Turnbull L. & Grace R. (1999) Family factors influencing out-of-home placement decisions. *Journal of Intellectual Disability Research* **43**, 219–33.
- Llewellyn G., Thompson K., Whybrow S., McConnell D., Bratel J., Coles D. *et al.* (2003) *Supporting Families: Family Well-Being and Children with Disabilities* (an ARC SPIRT collaborative research project). University of Sydney in collaboration with the Spastic Centre of NSW, Sydney, NSW.
- Lloyd T. & Hastings R. P. (2009) Parental locus of control and psychological well-being in mothers of children with intellectual disability. *Journal of Intellectual & Developmental Disability* **34**, 104–15.
- Mactavish J. B. & Schleien S. J. (2004) Re-injecting spontaneity and balance in family life: parents' perspectives on recreation in families that include children with developmental disability. *Journal of Intellectual Disability Research* **48**, 123–41.
- Morrissey P. (2005) *Family support 360*. Letter from the Commissioner, Administration on Developmental Disabilities. Available at: http://www.addfamilysupport360.org/3_10/commissioner_archive_2.asp (retrieved 8 August 2007).
- Olson D. H. & Barnes H. L. (1982) Quality of life. In: *Family Inventories* (eds D. H. Olson, H. I. McCubbin, H. Barnes, A. Larsen, M. Muxen & M. Wilson), pp. 55–67. Life Innovations, Inc., Minneapolis, MN.
- Parish S. L., Pomeranz A., Hemp R., Rizzola M. C. & Braddock D. (2001) *Family Support for Persons with Developmental Disabilities in the US: Status and Trends* (policy research brief). Institute on Community Integration, University of Minnesota, Minneapolis, MN.
- Park J., Turnbull A. & Turnbull H. R. (2002) Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children* **68**, 151–70.
- 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.
- Phelps K. W., McCammon S. L., Wuensch K. L. & Golden J. A. (2009) Enrichment, stress, and growth from parenting an individual with an autism spectrum disorder. *Journal of Intellectual & Developmental Disability* **34**, 133–41.

- Poston D. & Turnbull A. (2004) Role of spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Developmental Disabilities* **39**, 95–108.
- Poston D., Turnbull A., Park J., Mannan H., Marquis J. & Wang M. (2003) Family quality of life outcomes: a qualitative inquiry launching a long-term research program. *Mental Retardation* **41**, 313–28.
- Renwick R., Brown I. & Raphael D. (1998) *The family quality of life project*. Report to Developmental Services Branch, Ontario Ministry of Community and Social Services, Ontario, Canada.
- Rillotta F., Kirby N. & Shearer J. (2011) A comparison of two family quality of life measures: an Australian study. In: *Enhancing Quality of Life of People with Intellectual Disabilities* (ed. R. Kober), pp. 305–48. Springer, Dordrecht.
- Risdal D. & Singer G. H. S. (2004) Marital adjustment in parents of children with disabilities. A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities* **29**, 95–103.
- Ross P. & Cuskelly M. (2006) Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability* **31**, 77–86.
- Saito Y. & Turnbull A. (2007) Augmentative and alternative communication practice in the pursuit of family quality of life: a review of literature. *Research and Practice for Persons with Severe Disabilities* **32**, 50–65.
- Samuel P. (2007) *Psychometric evaluation of the Family Quality of Life Survey for low income minority families* (Research proposal submitted to the National Institute on Disability Research and Rehabilitation: CFDA # 84.133F). Wayne State University, Detroit, MI.
- Samuel P. (2010) *Final report: psychometric evaluation of the Family Quality of Life Survey for low-income, minority families*. Wayne State University, Detroit, MI.
- Samuel P. S., LeRoy B. & Janks E. (2010) *Inclusive communities: supporting families of children with developmental disabilities in Detroit*. Paper presented at the Inter-Country Meeting for Promotion of Inclusivity in Education, Employment, Health & Well-being of Persons with Disability in the South-East Asia Region, New Delhi, India.
- Schalock R. (2004) The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research* **48**, 203–16.
- Schalock R. L. & Verdugo M. (2002) *Handbook on Quality of Life for Human Service Practitioners*. American Association on Mental Retardation, Washington, DC.
- Schalock R. L., Brown I., Brown R. I., 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.
- Schalock R. L., Gardner J. F. & Bradley V. J. (2007) *Quality of Life of Persons with Intellectual and Other Developmental Disabilities: Applications across Individuals, Organizations, Systems, and Communities*. American Association on Intellectual and Developmental Disabilities, Washington, DC.
- Seligman M. & Darling R. B. (2007) *Ordinary Families, Special Children: A Systems Approach to Childhood Disability*. Guilford Press, New York.
- Seltzer M. M., Greenberg J. S., Krauss M. W., Gordon R. M. & Judge K. (1997) Siblings of adults with mental retardation or mental illness: effects on lifestyle and psychological well-being. *Family Relations* **46**, 395–405.
- Şenel H. G. & Akkök F. (1995) Stress levels and attitudes of normal siblings of children with disabilities. *International Journal for the Advancement of Counselling* **18**, 61–8.
- Skok A., Harvey D. & Reddihough D. (2006) Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. *Journal of Intellectual & Developmental Disability* **31**, 53–7.
- Smith-Bird E. & Turnbull A. P. (2005) Linking positive behavior support to family quality-of-life outcomes. *Journal of Positive Behavior Interventions* **7**, 174–80.
- Songjae J., Huh C., Kosciulek J. F. & Holecek D. F. (2004) Comparison of travel patterns of families with and without a member with a disability. *Journal of Rehabilitation* **70**, 38–45.
- Strohm K. (2002) *Siblings: Brothers and Sisters of Children with Special Needs*. Wakefield Press, Adelaide, SA.
- Summers J. A., Poston D. J., 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.
- Thompson L., Lobb C., Elling R., Herman S., Jurkiewicz T. & Hulleza C. (1997) Pathways to family empowerment: effects of family-centered delivery of early intervention services. *Exceptional Children* **64**, 99–113.
- Turnbull A. P. & Turnbull H. R. (2001) *Families, Professionals and Exceptionality*. Merrill Prentice Hall, New Jersey, NJ.
- Turnbull A. P., Turnbull H. R. & Blue-Banning M. (1994) Enhancing inclusion of infants and toddlers with disabilities and their families: a theoretical and programmatic analysis. *Infants and Young Children* **7**, 1–14.
- Turnbull A. P., Brown I. & Turnbull H. R. (eds) (2004a) *Families and Persons with Mental Retardation and Quality of Life: International Perspectives*. American Association on Mental Retardation, Washington, DC.
- Turnbull A. P., Turnbull H. R., Poston D., Beegle G., Blue-Banning M. *et al.* (2004b) Enhancing quality of life of families of children and youth with developmen-

- tal disabilities in the United States. In: *Families and People with Mental Retardation and Quality of Life: International Perspectives* (eds A. Turnbull, I. Brown & H. R. Turnbull), pp. 51–100. American Association on Mental Retardation, Washington, DC.
- Turnbull A. P., Poston D. J., Minnes P. & Summers J. A. (2007a) Providing supports and services that enhance a family's quality of life. In: *A Comprehensive Guide to Intellectual and Developmental Disabilities* (eds I. Brown & M. Percy), pp. 559–69. Paul H. Brookes Publishing Co., Baltimore, MD.
- Turnbull A. P., Summers J. A., Lee S. -H. & Kyzar K. (2007b) Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* **13**, 346–56. doi: 10.1002/mrdd.20174.
- Turnbull H. R., Beegle G. & Stowe M. J. (2001) The core concepts of disability policy affecting families who have children with disabilities. *Journal of Disability Policy Studies* **12**, 133–43.
- Verdugo M. A. & Schalock R. L. (2009) Quality of life: from concept to future applications in the field of intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* **6**, 62–4.
- Verdugo M. A., Córdoba L. & Gómez J. (2005a) Spanish adaptation and validation of the Family Quality of Life Survey. *Journal of Intellectual Disability Research* **49**, 794–8. doi: 10.1111/j.1365-2788.2005.00754.x.
- Verdugo M. A., Schalock R. L., Keith K. D. & Stancliffe R. J. (2005b) Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research* **49**, 707–17.
- Wang M., Turnbull A. P., Summers J. A., Little T. D., Poston D. J., Mannan H. *et al.* (2004) Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years. *Research and Practice for Persons with Severe Disabilities* **29**, 82–94.
- Wang M., McCart A. & Turnbull A. (2007) Implementing positive behavior support with Chinese American families: enhancing cultural competence. *Journal of Positive Behavior Interventions* **9**, 38–51.
- Webster R. I., Majnemer A., Platt R. W. & Shevell M. I. (2008) Child health and parental stress in school-age children with a preschool diagnosis of developmental delay. *Journal of Child Neurology* **23**, 32–8.
- 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.
- Yaoying X. (2007) Empowering culturally diverse families of young children with disabilities: the double ABCX model. *Early Childhood Education Journal* **34**, 431–4.
- Zabriskie R. B. & McCormick B. P. (2003) Parent and child perspectives of family leisure involvement and satisfaction with family life. *Journal of Leisure Research* **35**, 163–89.
- Zuna N., Summers J. A., Turnbull A. P., Hu X. & Xu S. (2011) Theorizing about family quality of life. In: *Enhancing the Quality of Life of People with Intellectual Disability: From Theory to Practice* (ed. R. Kober), pp. 241–78. Springer, Dordrecht.
- Zuna N. I., Turnbull A. P. & Summers J. A. (2009) Family quality of life: moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities* **6**, 25–31.

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