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Toward assessing family outcomes of service delivery: validation of a family quality of life survey

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Abstract

Background The concept of family quality of life (QoL) has emerged as an important outcome of service delivery for individuals with disabilities and their families. The present study describes the process of developing a tool to measure family QoL.
Methods and Results A total of 1197 respondents participated in a national field test. Through factor analysis, the survey was refined in several ways: (1) the preliminary 10-domain structure was reduced to a five-domain structure; (2) a total of 41 items were selected for the revised survey; and (3) wordings were clarified.
Conclusions The implications for future research and practice are discussed.

Keywords assessment, family outcomes, family quality of life survey, service delivery, validation

Introduction

Defining outcomes intended for consumers and specifying the services to be provided in order to achieve those outcomes is the foremost purpose of any service delivery system (Bailey *et al.* 1990; Gardner & Nudler 1999). As agencies have come to serve families in addition to children with disabilities, and as intervention has come to embrace more than remedial efforts on children's deficits, the prime consumers have come to include not only children with disabilities, but also their families (Dunst *et al.* 1991; Allen & Petr 1996; Turnbull *et al.* 2000). Therefore, emerging principles are that: (1) families' priorities and decisions should be respected; (2) services and supports should be provided to assist families in achieving their identified goals; and (3) service systems should be designed to improve the capacity of children with disabilities and their families to function in the natural environments of their communities (Duwa *et al.* 1993; Osher 1998).

As an outcome measure for services which meets these principles, researchers have proposed the concept of quality of life (QoL) (Murrell & Norris 1983; Fewell & Vadasy 1987; Schalock *et al.* 1989; Turnbull & Brunk 1997; Bailey *et al.* 1998; BCFD 1998; Schalock 1999; Gardner 2001; Wehmeyer & Schalock 2001). Several authors have emphasized that the QoL of individuals is related to that of those around them and have asserted that efforts to address the individual's QoL must also include consideration of the QoL

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perceived by those around them (Bailey *et al.* 1998; Dennis *et al.* 1993). For example, Osher (1998, p. 232) asserted that enhanced QoL for individuals and their families may be the 'only acceptable outcome' of services and policies. However, despite a long history of QoL studies, most research efforts have focused on conceptualizing and measuring individual QoL, with the notion of family QoL only recently receiving attention (ACSPD 1995; Bailey *et al.* 1998; Turnbull *et al.* 2000; Park *et al.* 2002). Therefore, it is not surprising that the conceptualization of family QoL primarily depends on the literature about individual QoL.

The definition of individual QoL has changed over the past 3 decades and has been defined differently by different researchers (Hughes & Hwang 1996; Schalock 1996, 1999; Brown 1997; Cummins 1997; Felce 1997; O'Boyle 1997). Regardless of the specific way in which QoL is defined, the concepts commonly include feelings of well-being, feelings of positive social involvement and opportunities to achieve personal potential. The synthesis of several important authors on QoL studies suggests six domains and associated indicators (SIRGQL 2000): (1) physical well-being, indicated by health, nutrition, mobility and activities of daily living; (2) emotional well-being, indicated by happiness, contentment, freedom from stress, self-concept and religious belief; (3) social well-being, indicated by intimacy, friendships, community activities, and social status and roles; (4) productive well-being, indicated by personal development in education or job, leisure and hobbies, choice and autonomy, and personal competency; (5) material well-being, indicated by ownership, financial security, food and shelter, and socio-economic status; and (6) civic well-being, indicated by privacy, voting access, civic responsibilities and protection under the law. The indicators listed here are not an exhaustive index, but rather, they provide an ongoing list that may be added to and refined continuously (Hughes & Hwang 1996; Schalock 1996; Cummins & Baxter 1997; Felce 1997; Gardner *et al.* 1997).

Quality of life for individuals with disabilities and their families

The uniqueness of each individual is important in evaluating QoL. At the individual level, the most prominent consideration may be whether or not the person has a disability. Schalock (1999) argued that QoL for people with disabilities encompasses the same domains as those without disabilities. On the other hand, Hatton (1998) asserted that the experiences of people with disabilities can be restricted because of the limits imposed by disability conditions, and in turn, these limited experiences may result in different indicators of QoL. It is necessary to remember not only that there may be broad, common domains which describe QoL across individuals, but also that specific indicators of an individual's QoL may extend beyond these general domains. Therefore, specific attention should be paid to the uniqueness of each individual and each family in conceptualizing and constructing a valid measurement for QoL (Borthwick-Duffy 1996).

Considering the complexity in defining family in contemporary society, in addition to the complexity of defining QoL, the definition of family QoL has even greater challenges. Turnbull *et al.* (2000) presented a recent definition of family and family QoL:

- *Family:* People who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis;
- *Family QoL:* Conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them.

Poston and her colleagues (in press) created their family QoL domains and indicators from the qualitative analysis of focus groups, as well as individual interviews with families of children with and without disabilities, and service providers/administrators. The analysis identified 10 domains of family QoL (Fig. 1). Although nine of the domains are relevant for all families, the tenth one, advocacy, is especially relevant for families who have a member with a disability. The proposed domains are listed below:

1 *Family interaction:* The relationships among family members and the relational environment in which the family operates.
2 *Daily life:* The daily, recurring activities of life which help meet individual and collective needs.
3 *Parenting:* The activities which adult family members do to help children grow and develop in multiple areas of life.

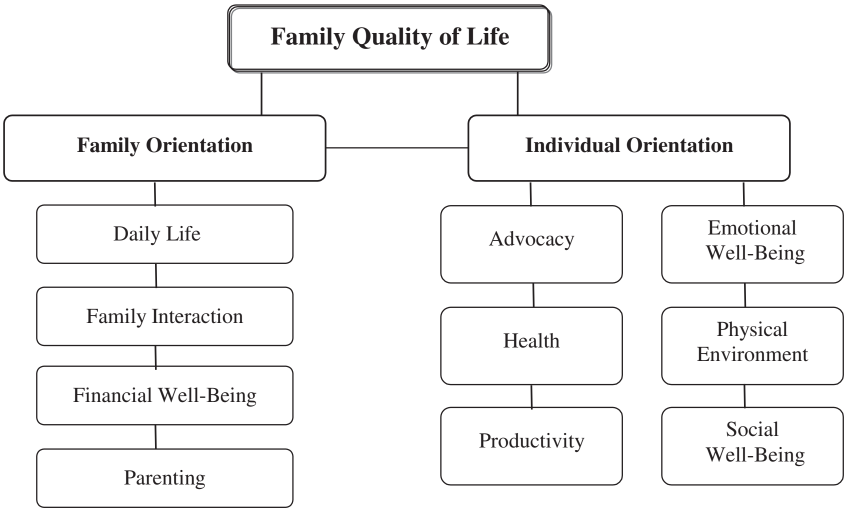

Figure 1 Ten domains of family quality of life.

4 *Financial well-being:* The financial means to pay, at least, for what the family needs and, in some cases, also for what it wants.
5 *Emotional well-being:* The emotional and internal aspects of life.
6 *Health:* The physical and mental health aspects of life and access to healthcare.
7 *Physical environment:* The physical environmental aspects of life (i.e. safety, space, comfort and access).
8 *Productivity:* The skills and opportunities to participate and succeed in various activities of life.
9 *Social well-being:* The relationships of family members with people outside the family.
10 *Advocacy:* The advocacy activities required by one or more family members which benefit the child with a disability and/or the family.

Family quality of life measurement issues

One of the first issues which needs to be considered with regard to the measurement of family QoL is the extent to which different family members' perspectives are necessary. Given that disability has a different meaning for each of the stakeholders in the environments of the child with a disability (e.g. the child, family members, friends and service provider), multiple perspectives may be essential in appropriating assessing QoL for families who have a member with a disability. Often, only one member of the family (e.g. the mother) is identified as the person who can best represent the child's interests (e.g. Guralnick 1994; Mahoney & Filer 1996). However, research has indicated that differences may exist among family members in their perceptions regarding service outcomes and life satisfaction (Upshur 1991; Crowley & Taylor 1994; Ainge 1995). For example, Upshur (1991) found that, while fathers perceived more benefits in learning how to be an advocate and in meeting other family members' needs during the first year of early intervention, mothers perceived more benefits in decreases in their own stress. Crowley & Taylor (1994) also found significant differences between mothers and fathers in their perceptions of family functioning, life stressors and sources of support. Thus, the inclusion of measures from multiple family members may be crucial in accurately reflecting the family outcome or family position for a given issue in families with a member who has a disability.

However, obtaining measures of family QoL from family members with disabilities presents unique challenges since they may not be able to respond to instruments in the same way as other family members. Previous methods of assessing individual QoL for people with disabilities have included surveys and questionnaires (e.g. Ferrans & Powers 1985; Cummins *et al.* 1994), interviews (e.g. Lehman 1988), and third-party interviews or surveys (e.g. Johnson & Cocks 1989; Ouellette-Kuntz & McCreary 1996). Gardner *et al.* (1997) presented a series of alternative methodologies for assessing individual QoL for people with severe cognitive or communicative disabilities: (1) interviewing the person with accommodated questions (e.g. using pictures or trying to discover preferences rather than communicating about choice); (2) interviewing people who know the person best (at least two people who have different relationships with the person with a disability); (3) observing interactions and environments (i.e. whether there are any opportunities offered to the person to engage in interactions with people in the normal flow of the person's day); and (4) checking the person's records or other programme documentation. Despite the time and expense required to obtain this kind of personalized assessment, such practices would enable people with disabilities to experience greater control and decision-making in characterizing both their individual and their family's QoL.

The inclusion of unique perspectives from families with different cultural and ethnic backgrounds may also be a relevant issue when measuring QoL outcomes for families who have a member with a disability. One such example is Vincent (1992), who conducted focus groups with Latino families of children with disabilities, and found that these families put a great deal of emphasis on the needs for information and support, socialization for the child, and help with separation from their children, rather than on other life areas. Instruments developed from a specific perspective may be inappropriate or, even if the instrument is appropriate, the analysis may not adequately consider the different perspective.

Finally, another important issue in measuring family QoL in general concerns the method of incorporating the different perspectives of each family member into an analysis of family outcomes or family attitudes. When data are collected from all family members, responses are often aggregated by calculating a mean across all family members. A limited amount literature has addressed the advantages and disadvantages of the various options for aggregating family data (i.e. Fisher *et al.* 1985; Ferketich & Mercer 1992; Lindsey-Davis 1993). One example is that of Brown & Timmons 1994), who investigated QoL perceived by adolescents with and without disabilities. The above authors presented the same questions to both students and their parents, and found a high percentage of agreement between the adolescents' and parents' perceptions. Although parents' responses were used only for calculating the agreement percentage without further analyses, it is notable that this study was the first reported in the literature that involved multiple family members in measuring QoL.

More recent statistical methods proposed for addressing couple or family data allow for the use of individual responses from the various members of the family, usually according to their role in the family, but do not require the aggregation of family data into a single score. For example, responses from multiple family members can be included within hierarchical linear modelling (Maguire 1999), or the amount of agreement or disagreement among family members across different domains can be modelled within structural equation modelling (Ferketich *et al.* 1991; Figuerdo *et al.* 1991; Sidani & Jones 1995). Both of these methods allow for the perspectives of each individual family member to be considered while simultaneously maintaining the family as the overall unit of analysis.

Developing a family quality of life survey

Based on this knowledge base, in the present authors describe the process of developing and validating the Family Quality of Life Survey (FQoLS), an instrument that may be used for multiple purposes, including for family-oriented research and for outcomes assessment. The research efforts reported in this study concerned the examination of the empirical structure of the hypothesized FQoLS domains and the revision of the items on the FQoLS as needed, as well as a preliminary examination of the psychometric properties for each of the domains. Although the authors are still in the process of validating the factor structure of the instrument, they report their findings from an initial national field test with the hope that others with interests in family outcomes may join their efforts.

Subjects and methods

This section presents (1) the background development of the survey, (2) procedures for the field test and (3) data analysis methods. Figure 2 shows the steps of the research project.

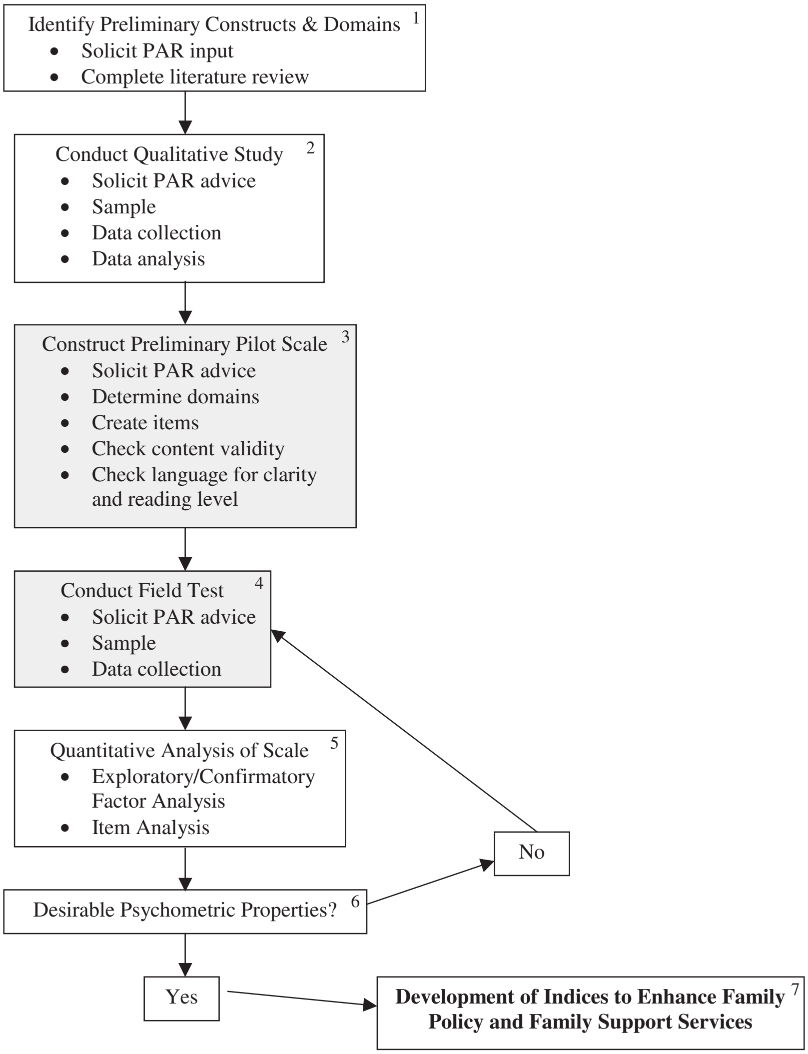

Figure 2 Major steps in the family quality of life research programme.

Background to the development of the Family Quality of Life Survey

Literature in the area of child and family outcomes, QoL studies, family assessments, and existing instruments which measure service outcomes and QoL was comprehensively reviewed to identify preliminary constructs of the instrument. The research team also worked with a Participatory Action Research (PAR) committee, which comprised researchers, family members and service providers, to (1) examine the initial conceptual framework and identified constructs, (2) address issues in family assessment, (3) formulate focus group questions and (4) obtain participation from diverse participants in data collection.

In order to identify important factors in family QoL for families of children with disabilities, 34 focus groups and 20 individual interviews were conducted in three US states: Kansas, North Carolina and Louisiana. The focus groups and individual interviews involved 171 individuals who included the family members (e.g. parents and siblings) of children with a disability, individuals with a disability, the members of families children without a disability, service providers and administrators. The participants were asked to talk about the important things for their families to have a good life together. The focus groups and interviews were audio-taped and transcribed verbatim. The transcripts from the focus groups and interviews (about 1900 single-spaced pages of transcripts) were placed in Ethnograph (5.0), a software program for qualitative analysis. From a constant comparative method of qualitative analysis (i.e. code categories are constantly compared to each other to get a general framework that properly interprets the data and the emerging interpretation is gradually reduced to produce a small set of higher-level concepts), 10 domains of family QoL were generated: advocacy, daily living, emotional well-being, family interaction, financial well-being, health, parenting, physical environment, productivity and social well-being (Fig. 1). The results of these focus groups have been thoroughly described in a manuscript that is currently in press (Poston *et al.* In press).

Development of the preliminary survey items

Approximately 12 items were written for each domain to cover the depth and breadth of the themes raised in the focus groups. Following Dillman's (1978) guidelines, attention was paid to three factors in writing questions to ensure that the survey was easy to use and required minimal respondent effort: (1) the type of information sought (i.e. attitudes); (2) the question structure (i.e. close-ended questions with ordered choices); and (3) specific question wording (i.e. simple, clear and non-biased). The preliminary survey prior to pilot testing was at approximately the eighth-grade reading level. In the survey, respondents rate the importance of each item to their family QoL on a five-point Likert scale, ranging from 'only a little important' to 'moderately important' to 'very important.

Based on the recognition that the survey is intended to measure the individual's perception of the whole family, multiple versions of the survey were developed in order to involve as many family members as possible, including versions for: (1) adult members of the family of the person with a disability; (2) adolescent siblings of the person with a disability; (3) individuals with a physical disability; and (4) individuals with a cognitive disability. These versions assessed the same indicators and domains, but the wording was modified for the different members (e.g. 'My child with a disability' for adults, 'My sibling with a disability' for siblings and 'I' for the individual with a disability). Recommendations from Dillman (1978) and consultation with two measurement experts guided the physical layout of the survey.

Pilot test and revision

A pilot test was conducted with colleagues, potential users of the data and people typical of the population. The pilot test participants included 16 family members, six service providers and five researchers. The participants were asked to review all the materials to be used in the field test, including the survey, cover letter, instruction sheet, family information booklet and consent form. A feedback form was given to participants to record their responses while they reviewed the materials. Each participant was then contacted via phone to provide feedback. The feedback forms included questions about readability, the length of the survey, adequacy of instruction and an open question for suggestions to improve the survey.

The biggest change made, based on the feedback from pilot participants, was to reduce the four versions of the survey to two versions: one for the adolescent or young adult with a disability (version 1); and the other for family members of a child with a disability (version 2). There were three main rationales for this change: (1) adult respondents liked the simpler wording of adolescent versions; (2) respondents indicated that families could be confused by the four different versions of survey which, in turn, may result in their completing the incorrect version of survey; and (3) the easier and simpler wording of the version for individuals with a cognitive disability was not necessary because these individuals would still need to have their family members assist them in completing the survey. As a result, the items were rewritten or simplified to a sixth-grade reading level. After several repetitive items were deleted from the scale, the scale was finalized with a total of 112 items. In addition to reducing the number of versions, several revisions were made in the survey based on the feedback from the pilot test. Revisions included clarifying some items, providing specific examples for some items and removing redundant items. After all changes were made, the survey was translated into a Spanish version.

Procedures for the field test

Thirteen states which represent diverse geographical areas of the USA assisted with the field test. The states included were:

- West: Arizona, California and Washington;
- Midwest: Illinois and Minnesota;
- North-east: Massachusetts, New York, Pennsylvania and Vermont; and
- South: Louisiana, North Carolina, South Carolina and Texas.

The number of families needed from each state was determined proportionally based on the population of the state, and efforts were made to include urban, suburban and rural geographical areas in each state. For example, in the state of Minnesota, the invitation packets were sent to 200 families from an urban school district, 100 families from a suburban school district and 50 families from a rural school district. Once the number of families needed from each geographical area was decided, the research team contacted several school districts in the area to ask for their participation in the field test. If the district agreed to assist with the sampling process, some guidelines for sampling were provided: (1) exclude the children who receive speech services only; (2) alphabetize the names of children with disabilities; and then (3) select every *n*-th child based on the total number of children that they served. For example, when a sample of 50 children is needed out of the 600 children with disabilities whom the district serves, every twelfth child would be selected. For the purpose of developing a psychometrically sound instrument, the general recommended ratio of the number of respondents to the number of items is 5:1 for exploratory factor analyses (e.g. Bentler 1976). Based on this recommendation, the present authors' goal was to obtain a sample of 560 families (112 items × 5 people per item). They expected to get about a 20% response rate to the initial invitation, based on previous studies. Out of that 20%, the authors expected the participation of approximately 705–7580%. Thus, a total of 3 935 686 invitation packets were sent to families in the 11 states.

In addition to the public schools, the Grassroots Consortium, a nation-wide constellation of parent organizations for families of children with disabilities from culturally and linguistically diverse backgrounds, was contacted in order to increase the diversity of the sample. The Grassroots Consortium groups from five states participated in the study: California, Minnesota, New York, Massachusetts and Washington. The Grassroots organizers estimated the number of surveys needed at each location, and the administration of the instrument for the Grassroots participants was then conducted in small groups, so that language assistance could be provided for those participants who did not speak English or Spanish.

For the rest of the sample, the families of the children chosen from the enrolment list were sent invitation packets which contained initial letters and response postcards. The initial letter briefly described the importance of the study, the sampling process (i.e. how the participants were selected and how their addresses were obtained), the amount of time needed to fill out the survey (approximately 35 min), the honorarium for the participation and contact information to ask questions. In the response card, families were asked to check how many family members aged 13 years or older were willing to participate in the study, and to indicate whether their family members wanted an English or Spanish version of the survey.

Families who agreed to participate sent the postcards to the family QoL research team. A packet of survey materials was sent to the family within a week after the response card was received. Each packet included an instruction sheet, the surveys for each family member aged 13 years or older, consent forms, a family information booklet, a payment form and a self-addressed return envelope. The instruction sheet included descriptions of how to complete the survey, the role of the 'family survey captain' (e.g. distribute surveys to family members, encourage family members to fill out the survey and collect completed surveys) and a checklist of materials which should be returned. The family information booklet requested data about the gender, age and role in the family (e.g. father, mother or relative) of each family member, geographical area (e.g. large city, urbanized area, small city or rural), the various agencies from which the family was receiving services at the time of completing the survey, the income of the family and the number of family members supported by that income, and information about the child with disabilities (i.e. age, gender, and type and severity of disability). A reminder postcard was sent to the families who did not return the surveys within one month after the survey was mailed.

Return rate

Among the 3 935 686 families who received the invitation packets, a total of 160 invitation packets were returned as non-deliverable. There were 662 families (family units) who returned the response cards to indicate that they were willing to participate in the present study (response rate to the invitation = 18%). Among the 662 families who received the survey packets, 340 families (988 individual family members) returned the surveys (response rate to survey = 51%). Among the 152 families included by the Grassroots Consortium, 119 families (209 individual family members) returned surveys (response rate to survey = 78%). Thus, responses were analysed from a total of 459 families which comprised 1197 individuals.

Participants

Table 1 summarizes the demographic information for the 1197 individual respondents. Out of these respondents, 194 (16%) were adolescents or young adults with a disability. Out of those respondents without a disability over the age of 18 years ($n = 924$), 59.1% of the respondents were women and 39.7% were men. Out of the respondents over 18 years of age, 47.3% of the respondents were employed full-time, 17.4% were employed part-time and 24.9% were not employed (e.g. stay-at-home parent or caregiver, retired, public assistance pay, or disability). Out of the family members of the person with a disability who responded, approximately 62.9% of the respondents were parents, 20.0% were siblings and 10.7% were extended family members. The overall age range was 13–96 years (mean = 34.95 years, SD = 14.9 years).

Table 2 summarizes the information about the 459 family units. The sizes of the family ranged from one to nine people (mean = 2.7). Approximately 22.2% of the families had an annual income before taxes of less than US$16 500 and 32.5% of the families had annual income over US$50 000. By geographical area, about 28.8% of the families lived in large cities or metropolitan areas where the population is greater than 200 000, 16.3% lived in urbanized areas where the population is between 50 000 and 200 000, 29.4% lived in towns or small cities where population is between 2500 and 50 000, and 16.3% lived in rural areas where population is less than 2500. Approximately 15.5% of the families rated the severity of their child with disabilities as mild, 38.3% as moderate, 22.4% as severe, 10.9% as very severe and 4.4% as unknown.

Results

As previously mentioned, 112 items were administered which were hypothesized to reflect the 10 domains of QoL. The importance of each item was ranked on a five-point scale. Importance was specifically chosen for two reasons. First, an instrument designed to assess outcomes such as QoL should include those aspects which are of greatest significance to the population of interest. Secondly, importance should represent a more stable construct with which to evaluate the psychometric properties of the instrument because it is less likely to vary over time than a state measure such as satisfaction. Initially, it was anticipated that the items reflecting general family QoL (85 items) and those reflecting disability-specific QoL (27 items) would be factor-analysed together. However, although issues relating to disability are certainly an integral part of evaluating family QoL, the severity of the disability of the child could result in different factor structures across families, potentially affecting the overall stability of the instrument. To prevent this, disability-specific items were analysed separately from general QoL items.

Two different data sets were created for analysis, one with responses of the primary caregiver(s), as indicated on the survey forms ($n = 428$ families), and another with the family as a whole ($n = 459$ families). Because 31 families did not indicate that a primary caregiver had responded to the survey (e.g. only a sibling of the child with a disability responded), only 428 families were included in the primary caregiver data set. In some families, two adults indicated that they were primary caregivers. In that case, the ratings of the two caregivers were averaged. Two scoring examples are given. If the father (primary caregiver

Table 1 Field test respondent demographics: individual information ($n = 1197$)

Variable	*n*	%
Gender		
Female	664	55.5
Male	504	42.1
Missing	29	2.4
Age range		
13–20	298	24.9
20s	143	11.9
30s	238	19.9
40s	314	26.2
50s	98	8.2
60s	32	2.7
Above 70	16	1.4
Missing	58	4.8
Hispanic or Latino origin		
Yes	171	14.3
No	961	80.3
Missing	65	5.4
Race and ethnicity		
American Indian/Alaskan Native (Hispanic/Latino origin)	3	0.3
Asian or Pacific Islander (Hispanic/Latino origin)	1	0.1
Black or African American (Hispanic/Latino origin)	4	0.3
White (Hispanic/Latino origin)	23	1.9
Other (Hispanic/Latino origin)	43	3.6
American Indian or Alaskan Native (non-Hispanic/Latino)	21	1.8
Asian or Pacific Islander (non-Hispanic/Latino)	70	5.8
Black or African American (non-Hispanic/Latino)	134	11.2
White (non-Hispanic/Latino)	543	45.4
Other (non-Hispanic/Latino)	8	0.7
Missing	347	29.0
Participant relationship to child with a disability		
Parents	631	52.7
Sibling	201	16.8
Other relative	107	8.9
Non-relative	22	1.8
Missing	42	3.5
Adolescent/young adult with a disability	194	16.2
Marital status		
Married	565	47.2
Widowed	26	2.2
Divorced	68	5.7
Separated	27	2.3
Never married	298	24.9
Missing	19	1.6
Adolescent/young adult with a disability (not collected)	194	16.2
Employment status		
Employed full-time	452	37.8
Employed part-time	183	15.3
Working without pay in family business or farm	16	1.3
Unemployed but looking	91	7.6
Not employed (stay-at-home, retired, disability, etc.)	360	30.1
Missing	95	7.9

Table 1 *Continued*

Variable	*n*	%
Highest level of education completed		
No schooling completed	51	4.3
6th grade	135	11.3
9th grade	75	6.3
10th, 11th or 12th grade but no diploma	146	12.2
High school graduate or GED	210	17.5
Some college or post high school training but no degree	231	19.3
Associate degree (AA, AS, etc.)	85	7.1
Bachelor's degree (BA, AB, BS, etc.)	129	10.8
Graduate degree	88	7.4
Missing	47	3.9

1) rated a certain item as (5) 'very important', the mother (primary caregiver 2) rated it as (3) 'moderately important' and the sister rated it as (5) 'very important', the primary caregiver score would be 4 [(5 + 3)/2] and the family score would be 4.33 [(5 + 3 + 5)/3]. However, if in a different family only the mother rated the same item as 4 and a brother rated it as 2, then the primary caregiver score would be 4 and the family score would be 3 [(4 + 2)/2]. Although the primary caregiver data were used in the analyses to follow, the total family data yielded similar results. Consequently, only one set of analyses is reported.

Within the primary caregiver data set, an exploratory factor analysis with principal axis extraction was used to investigate the structure of the importance ratings of the items and potentially reduce the number of items. Because the items were designed to measure 10 separate domains expected to correlate, 10 factors were originally specified and promax rotation was used to produce an interpretable solution. After rotation, the first factor accounted for approximately 35% of the variance, with the remaining nine factors accounting for approximately 18% of the variance. The 10 factors extracted in this manner did not conform to the hypothesized structure. Next, a second exploratory factor analysis was conducted with the extraction criteria of eigenvalues over 1 to investigate other alternative structures. Although 21 factors were extracted with eigenvalues over 1, only 15 were conceptually interpretable. The remaining factors had too few items with substantial loadings (i.e. >0.4), and these factors were not interpreted. Some of the hypothesized domains appeared to be reflected in more than one factor (e.g. items for Family Interaction and Parenting each appeared in two factors). The other factors appeared to represent subsets of other hypothesized domains, such as Safety, originally part of Physical Environment.

In order to reduce the data to a minimum number of general but conceptually meaningful factors, additional exploratory factor analyses (also with principal axis extraction and promax rotation) were conducted. At each step, items were removed based on the following criteria: items which did not load above 0.3 on any factor, items rated in the bottom of the importance distribution (mean of ≤€4.2 out of 5), items which loaded repeatedly in isolation from other similar items, or items whose content or loading patterns appeared to reflect individual QoL rather than family QoL. At the end of this process, 46 items were removed, and two pairs of items with similar wording were averaged into two new items, for a total of 48 items removed, leaving 37 non-disability-related items.

From these items, a new factor structure emerged. These new factors reflected coherent constructs representing Family Interaction, Parenting, Health and Safety, and a General Resources factor, which included ability to get caregiving help, financial help, time and transportation, for example. Based on a combination of face validity and factor analytic results, items were assigned to the four new factors and preliminary internal reliabilities were computed.

Table 2 Field test respondents' demographics: family information ($n = 459$)

Variable	*n*	%
Number of family members completed the survey		
1	108	23.5
2	122	26.6
3	97	21.1
4	62	13.5
5	44	9.6
6	8	1.7
7	3	0.7
8	1	0.2
9	1	0.2
Missing	13	2.8
Size of the community where the family lives (population)		
Large city or metropolitan area (greater than 200000)	132	28.8
Urbanized area (between 50000 and 200000)	75	16.3
Town or small city (between 2500 and 50000)	135	29.4
Rural area or town (less than 2500)	75	16.3
Missing	42	9.2
Annual family income before taxes		
Less than 16500	102	22.2
Between $16500 and $24999	52	11.3
Between $25000 and $34999	64	13.9
Between $35000 and $49999	57	12.4
Between $50000 and $74999	84	18.3
Over $75000	65	14.2
Missing	35	7.6
Gender of the child with a disability in the family		
Female	156	34.0
Male	267	58.2
Missing	36	7.8
Disability severity of the child with a disability in the family		
Mild	71	15.5
Moderate	176	38.3
Severe	103	22.4
Very severe	50	10.9
Unknown	20	4.4
Missing	39	8.5
Disability type of the child with a disability in the family[a]		
Mental retardation	149	32.5
Hearing impairments including deafness	43	9.4
Speech or language impairments	190	41.4
Vision impairments including blindness	67	14.6
Serious emotional disturbance	41	8.9
Orthopedic impairments, physical disability	98	21.4
Autism	65	14.2
Traumatic brain injury	20	4.4
Specific learning disabilities	121	26.4
ADD or ADHD	74	16.1
Developmental delay	95	20.7
Mental illness	22	4.8
Other health impairments	64	13.9
Other disability	71	15.5
Missing	23	5.0

[a] The total of the disability type cases is not equal to 459 because some children have multiple disability conditions (the total of percentage is also larger than 100).

Cronbach's alphas were 0.90 for Family Interaction (11 items), 0.82 for General Resources (nine items), 0.87 for Health and Safety (eight items), and 0.86 for Parenting (nine items). Items were then combined to eliminate redundancy or reworded for clarity, leaving eight designated new items for each factor.

The 27 disability-related items were also subjected to a series of exploratory factor analyses using principal axis extraction and promax rotation. The initial solution revealed five factors, with the first factor and remaining four factors accounting for approximately 39% and 21% of the variance, respectively. At this point, eight items were removed which either did not load highly on any of the factors, consistently loaded in isolation from the other items or were rated in the bottom of the importance distribution (mean of ≤€4.2 out of 5). Subsequent analysis revealed two interpretable factors, one dealing with issues related to the support available to the child with the disability to do various things, and another related to advocacy, or the ability or knowledge of someone in the family to obtain needed services. Although advocacy is an important part of life in families who have children with disabilities, the present authors feel that the accessibility of support services rather than the amount of advocacy required to receive them should be the focus for evaluating family QoL. The 19 items were reworded accordingly, and redundant items were combined or eliminated. The final scale, Support for Persons with Disabilities, consists of eight items which incorporate different areas of life in which supportive services might be utilized, such as: making progress at school, work or home; making friends; obtaining government benefits; or receiving good medical care.

The evolution of the factor structure from the 10 factors to the five is depicted in Fig. 3. Some sample questions from the five factors are provided in Appendix 1.

Discussion

Though the topic of QoL has been investigated and attempts have been made to measure the concept for more than 60 years (Thorndike 1939), unsolved questions supersede solved ones. Considering that the concept has affected and will continue to affect an entire service delivery system (Schalock 1999), a discussion of family QoL as a measurable construct needs to be continued and expanded. The present study is one of the beginning efforts for such discussions by demonstrating the process of developing and validating a measurement tool that assesses family QoL. Based on the responses from the family members of children with disabilities, this study identified the construct indicators which were perceived as highly important by family members. This section provides a discussion of (1) the limitations of the

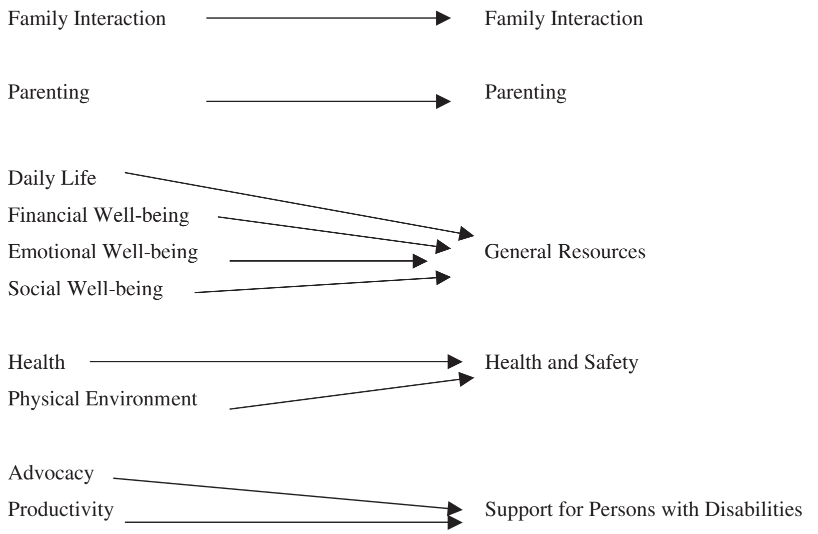

Figure 3 Evolution of the factor structure.

study, (2) the implications for service delivery and (3) the implications for future research.

Limitations of the present study

Several limitations need to be considered in interpreting the findings presented in this study. First, the majority of the field test was administered via pencil and paper. Considering that each family has unique needs (e.g. family members who cannot read), more diverse data collection methods which are sensitive to respondent's unique needs (e.g. interview) would enrich the data. Secondly, the survey used in the field test was quite long (112 items), and thus, this response burden may have eliminated potential respondents. Thirdly, the instrument required the participants to rate only the importance of each of the QoL items. The present results indicate that family members do appear similar in their perceptions of what is important for family QoL. However, it is important to note that the extent to which the similarity of response across family members for satisfaction with QoL has yet to be determined. As explained earlier, the measurement of traits tends to be more psychometrically reliable than the measurement of states, such as satisfaction. Additionally, it is more likely that family members will differ in the extent to which they are satisfied for a given item than the extent to which they think a given item is important. The present authors will address the stability of this instrument as a whole as well as the stability of response across family members for satisfaction with QoL in subsequent research. Finally, this study did not assess test–retest reliability. One of the intended uses of the final instrument will be to examine outcomes and changes in outcomes for families; the degree to which this change reflects an actual change in outcome rather than simple measurement variation has yet to be assessed.

Implications for service delivery

The present study focused on the validation of a scale that can be used as an outcome measure of service delivery. The positive impacts of such attention to comprehensive family outcomes are the promotion of a family-centred service delivery system and facilitation of active participation of families in service delivery. According to Schalock (1999, p. 3), QoL provides 'the vehicle through which consumer-referenced equity, empowerment, and increased life satisfaction could be achieved'. In other words, the concept of family QoL is consistent with the demands of the field which require individualized and appropriate education and services for children with disabilities and their families. Families as consumers will become increasingly involved in identifying and assuring the authenticity of indicators of their QoL, and in turn, the indicators identified by them will be the ideal goal and content of services.

Secondly, the use of the current scale to identify unmet needs can be instrumental in guiding policy that may influence resource allocation decisions. Although this study only inquired about the importance of the indicators for the purpose of validation, subsequent studies will ask about consumers' satisfaction in order to represent the interests of certain groups. For example, family QoL data for a defined group of interest (e.g. families with low socio-economic status or from diverse cultural backgrounds) may be compared to total population norms and ranges to establish the social equity of a group's circumstances (Felce 1997), which should enable policy makers to identify and prioritize the gaps to be filled. The measurement of family QoL could have powerful social policy implications considering the national and international recognition of QoL as a philosophical guide and legal principle in policy formation (SIRGQL 2000). For example, the data from family QoL outcome measures could be used in order to protect and expand early intervention services which document QoL enhancement.

Thirdly, attending to the notion of family QoL as an outcome could create innovations in staff training and personnel preparation. Service providers are challenged to implement quality enhancement techniques which focus on what programme personnel and services can do to enhance a family's perceived QoL (Schalock 1999). The new requirements for staff training have changed dramatically over the past few decades. The evaluation of service delivery and providers' own performance is now based on broad family QoL criteria, as well as on specific target area of services (Dennis *et al.* 1993). Additionally, staff must deal not only with the child with a disability, but also with her or his family members, advocates and a range of other professionals, a process that requires collaboration skills such as networking, communication and human management skills (DeGangi *et al.* 1994; Dunst *et al.* 1994; Lowenthal 1994; O'Connor 1995; Dinnebeil *et al.* 1996; Roberts *et al.* 1996; Cummins & Baxter 1997; Romer & Umbreit 1998). Finally, staff must work with children with disabilities and their families from culturally, linguistically or socioeconomically diverse backgrounds by recognizing and developing their particular strengths and resources, necessitating culturally competent professionals respectful of and sensitive to different values, communicating styles, beliefs and traditions (Lynch & Hanson 1998; Kalyanpur & Harry 1999; Park & Turnbull 2001).

Implications for future research

The current study provides several implications for subsequent research. First, just as the concept of family QoL calls for the active participation of families in planning, implementing and evaluating service delivery, the notion of family QoL as an outcome urges researchers to involve families in their research efforts. Recent innovative research practices such as PAR reflect the influences of the concept in academia (Lovitt & Higgins 1996; Sample 1996; Carnine 1997; Meyer *et al.* 1998; Santelli *et al.* 1998; Turnbull *et al.* 1998).

Secondly, although not yet addressed comprehensively in research, individual differences (even within a family) in terms of age, gender, disability conditions, stage in the life cycle or role in the family have emerged as new areas for consideration in measuring family QoL (Borthwick-Duffy 1996; Halpern 1993). For example, when the parents or siblings of a young child with special needs also have disabilities, techniques to accommodate their exceptionality may be needed.

Thirdly, future research efforts should be extended to evaluate appropriate ways with which to include data gathered from multiple family members within a family. One of the family centred premises is that services should be administered to the family as a collective unit. Therefore, family QoL analyses will be meaningful when conducted with the data from multiple family members rather than just a single member, and when the family serves as the unit of analysis, by simultaneously incorporating the scores of multiple family members within an appropriate model. The present study demonstrated one possibility of treating a family as a unit of analysis by using the average score as a representative value both across all family members and the primary caregivers. However, because the nature and degree of different family members' impact on the overall family is not homogeneous, future studies may need to implement alternative ways of including data from multiple family members within a family to best reflect the family's perceptions (Turnbull *et al.* 2000).

In conclusion, the concept of family QoL as an outcome of service delivery calls for partnerships among family members of individuals with disabilities, service providers, researchers and policy makers. As these stakeholders work together to (1) identify important QoL themes in the families of individuals with disabilities, (2) develop and implement quality services based on the identified themes, (3) research and debate the conceptualization and measurement of family QoL, and (4) develop policies to enhance family QoL, 'the first decade of the 21st century will be turned into an exciting and active time' (Schalock 1999, p. 21) where children with disabilities and their families pursue and enjoy enhanced QoL.

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Appendix 1 Family Quality of Life Survey Sample questions

	For my family to have a good life together, how important is it that . . .				
Sample question	**A little important**	**Somewhat important**	**Moderately important**	**Very important**	**Critically important**
My family enjoys spending time together.					
My family is able to handle life's ups and downs.					
My family members have a way to get to the places they need to be.					
My family members have friends or others who provide support.					
My family gets medical care when needed.					
My family feels safe at home, work, school, and in our neighborhood.					
Adults in my family have the information needed to make decisions about the children.					
Family members help the children learn to be independent.					
My family member with a disability has support to be included in community activities.					
My family has support to get the government benefits that our family member with a disability needs.					