

Conceptualizing and measuring family quality of life

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Abstract

Background Increasing emphasis on family-centred approaches to services and supports for families of children with disabilities has surfaced the issue of accountability for family outcomes. We present a review of literature about the impacts of children with disabilities on families as a backdrop to proposing family quality of life as a concept that encompasses impacts of disability and one that can be used to assess the impact of supports and services on families.

Method We briefly introduce the Beach Center Family Quality of Life Scale, providing information about its factor structure, reliability and convergent validity.

Results The Beach Center Family Quality of Life Scale contains 25 items assessing family ratings of importance and satisfaction with five domains: Family interaction, Parenting, Emotional well-being, Physical/material well-being and Disability-related supports.

Conclusion We present a framework for utilizing a measure of family quality of life as a long-term outcome in concert with other short-term measures of service outcomes for families.

Keywords disability, family, measurement, outcomes, quality of life

Introduction

Throughout the last two decades, the developmental disabilities field has come to a consensus that providing family support and delivering services using family-centred approaches are established core concepts of disability policy and practice (Turnbull *et al.* 2001). We recognize that disability impacts the whole family (Turnbull *et al.* 2006), that children are served best in the context of their family life (Parish *et al.* 2001), and that professionals working in partnership with families are better able to meet the needs of the child with a disability (Dunst 1997).

The emphasis on families, both as partners in serving children and adults with disabilities and as recipients of support services themselves, gives rise to the question of accountability. How are families impacted by a member with a disability, and which of these impacts should services address? What supports and services produce optimal outcomes for families? Finally, what are the most efficient ways to capture a comprehensive index of family outcomes as a way to measure the effectiveness of services?

We define family outcomes as impacts (either positive or negative) experienced by families as a result

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of supports and services for themselves and/or their children with disabilities. Determining appropriate conceptualizations of family outcomes requires an understanding of the impacts of members with a disability on families. Family supports and services should be targeted on ameliorating negative and strengthening positive impacts. With that in mind, we will present a review of literature related to the impacts of children with disabilities on families, with an eye to assessing the applicability these impacts (or their reduction) as outcomes for family support services. We then (1) propose the construct of family quality of life as a concept representing a broader range of these impacts; and (2) briefly present a new tool, the Beach Center Family Quality of Life Scale, as an authentic and efficient device to measure the construct of family quality of life.

Review of research on three types of impacts

Historically, research on the impacts of children with disabilities on families falls into three broad themes. These include studies of (1) stress, depression or caregiving burden arising from the child's disability; (2) how the child affects family functioning; and (3) eco-cultural adaptations to the family's routine occasioned by the disability.

Stress, depression or caregiving burden

One set of potential impacts of children with disabilities on family life focuses on the presumed negative impacts of stress, depression or caregiving burden (Crnic *et al.* 1983; Gallimore *et al.* 1996). Using stress as an example of these constructs, research has reported mixed results. Some research has reported that parents of children with disabilities face more challenges and have higher stress levels compared to parents whose children do not have disabilities (Warfield *et al.* 1999; Olson & Hwang 2001). Alternatively, other researchers have reported no difference in stress levels or depression (Singer 2005). Stress impacts appear to vary with the characteristics of the child, with parents who have children with problem behaviour reporting higher levels of stress (Baker *et al.* 2002). Services such as respite care and family support appear to reduce stress levels in families (Aniol *et al.* 2004).

Three limitations have been raised regarding reliance on stress, depression or caregiving burden as a measure of family impact. First, these constructs are relatively unidimensional, focusing only on psychosocial adjustment, while the impact of disability appears to be more complex and multidimensional across a number of aspects of family life. Second, these measures range from global measures to specific parenting measures (Lessenberry & Rehfeldt 2004); thus, the use of these psychosocial measures for intervention research or evaluation would need to be selected carefully to match the intended purpose of the intervention. Third, the constructs of stress, depression or caregiving burden have a negative connotation and carry an assumption of negative valence in their measures; such an orientation may miss potential positive or neutral impacts of disability on the family (Taunt & Hastings 2002).

Family functioning

A more neutral and multidimensional construct can be found in studies of family functioning (Walsh 2003). These concepts are derived from family systems theory and focus on dimensions of the interactional processes occurring within families: communication, cohesion, flexibility, role performance and coping processes (Olson & Gorall 2003). Examples of measures of family functioning include the *Family Adaptability and Cohesion Scales* (Olson *et al.* 1992) and the *Family Environment Scale* (Moos & Moos 1986).

Family functioning measures have been used to study the impact of children's disabilities on the family (Dyson *et al.* 1989; Van Riper *et al.* 1992). Family functioning measures have also been used as mediating variables to investigate the impact of various types of family relationships on child development (Hauser-Cram *et al.* 2001) or as a predictor of parental involvement in programmes (Gavidia-Payne & Stoneman 1997). We could find no recent studies utilizing these measures to evaluate the impacts of supports and services on families.

Eco-cultural adaptation

A third line of research has focused on defining the accommodations to family life required as a result of the child's disability. The concept holds that families

have a daily routine for living, working and socializing; therefore, the impact is the degree to which the child's disability requires the family to reorganize or *accommodate* their routine (Diamond & Kontos 2004). This concept has matured through a programme of research dating back to the 1980s and has resulted in the identification of accommodation domains such as socio-economic status, career work orientation, structuring of home environment, family workload related to the child, connectedness of the parents and use of information from professionals. Assessment of accommodations is achieved through the *Ecocultural Family Interview* (Weisner *et al.* 1997), an open-ended interview with a system for rating the accommodations in each domain.

Applications of this approach have resulted in studies of variations in accommodations based on the child's characteristics (e.g. medical needs, behaviour), and by such family characteristics as poverty and resources (Bernheimer *et al.* 2003). In a search of research databases, we were unable to find application of this assessment process to an evaluation of impacts of supports and services. The lengthy interview protocol and the training requirement for interviewers and scorers may place limitations on the use of this approach as an outcome measure for intervention research or programme evaluations.

Family quality of life as an impact of disability on families

Leaders in the disability field have called for family quality of life as a valued outcome of policies and services (Bailey *et al.* 1998; Dunst & Bruder 2002; Turnbull *et al.* 2004). Brown and colleagues (Brown *et al.* 2003) from Canada partnered with researchers from Australia and Israel to develop a theoretical framework and survey instrument for gathering information on family quality of life. The survey gathers quantitative and qualitative data in nine key areas: health, financial well-being, family relationships, support from other people, support from services, careers and preparing for careers, spiritual and cultural life, leisure, and community and civic involvement. The survey enables families to assess their *opportunities* for participation, their *initiative* in taking advantage of opportunities, their *attainment* in accomplishing things important to them, and their

satisfaction with their overall family life. Based on interviews with families who have children ages 10–36, they concluded family relationships, spiritual/cultural beliefs, and careers appeared to be strong contributors to family quality of life. Families expressed lower satisfaction with the lack of practical support extended by family, friends, and neighbours and with opportunities for leisure time as a family. They also expressed frustration with disability services that did not always appropriately address their priority needs.

Olson & Barnes (1982) used a subjective conceptualization to define family quality of life as a family's sense of the fit between themselves and their environment. The measure, entitled *Quality of Life*, is intended for families of typically developing adolescents. It assesses life satisfaction in 12 domains for the Parent Form of the scale and 11 domains for the Adolescent Form. In a search of research databases, we could find no published studies utilizing this scale within the last 20 years.

In the next section, we summarize the work to date on a new measure, the Beach Center Family Quality of Life Scale, designed specifically for families of children with disabilities. Our purpose was to create a family outcome measure that would be useful to policy makers, service providers and families in evaluating the quality of programmes. Specifically, a useful measure would synthesize the three themes of family impact reviewed above within a broader conceptualization of family quality of life. Further, it should represent the authentic voices and perceptions of the families of children with disabilities, reflecting their understanding of family quality of life. A useful measure would be short, easily administered and compatible with other service-related measures. Finally, a useful measure would focus on the family as a whole and would be relevant to all members of the family.

The Beach Center Family Quality of Life Scale: implications for research and practice

The Beach Center Family Quality of Life Scale was developed from a grounded theory, qualitative study of perceptions of families of children and youth with disabilities about the meaning of family quality of life (Poston *et al.* 2003). We then developed a statistical model of the qualitatively derived items, using explor-

atory factor analysis to reduce the data and develop subscales (Park *et al.* 2003). We conducted two additional studies to confirm and refine the factor structure and establish further validity and reliability of the scale. More details on these two studies, as well as detailed psychometric properties, can be found in other publications (Wang *et al.* 2004; Beach Center on Disability 2005; Mannan 2005). Analyses confirmed a five-factor solution and resulted in a 25-item scale encompassing five domains of family quality of life: Family interaction, Parenting, Emotional well-being, Physical/material well-being and Disability-related support (see Table 1). Item models for each factor had good to excellent fit for both importance and satisfaction (Beach Center on Disability 2005). The overall scale structure resulted in excellent fit for the subscale-level models for both importance and satisfaction ratings. Convergent validity measures were significantly correlated with their hypothesized subscales – Family APGAR (Smilkstein *et al.* 1982) to the Family interaction subscale and Family resource scale (Dunst & Leet 1985) to the Physical well-being subscale. Test–retest reliability correlations were significant for both importance and satisfaction for all subscales.

Implications for research

Research on impacts of services on families has used different conceptualizations than research on the impacts of children with disabilities on families that we described previously. Several frameworks for conceptualizing family outcomes of services have been proposed (Bailey *et al.* 1998; Roberts *et al.* 1999; Bailey & Bruder 2004). Common elements include outcomes related to (1) empowering parents to gain advocacy and partnership skills; (2) enhancing the family's ability to parent their child effectively; (3) helping families build support networks; and (4) enhancing overall family health and well-being.

We propose a relationship between these suggested outcomes of family supports and services and family quality of life; the short-term outcomes of supports and services (e.g. empowerment) lead to the ultimate outcome of family quality of life. Therefore, agencies may want to use specifically tailored measures to assess these short-term outcomes and be held accountable only for the supports and services they provide, while simultaneously assessing the overall,

Table 1 Beach Center Family Quality of Life Scale domains and items

For my family to have a good life together ... How *satisfied* am I that ...

Family interaction:

My family enjoys spending time together.
 My family members talk openly with each other.
 My family solves problems together.
 My family members support each other to accomplish goals.
 My family members show that they love and care for each other.
 My family is able to handle life's ups and downs.

Parenting:

Family members help the children learn to be independent.
 Family members help the children with schoolwork and activities.
 Family members teach the children how to get along with others.
 Adults in my family teach the children to make good decisions.
 Adults in my family know other people in the children's lives (i.e. friends, teachers).
 Adults in my family have time to take care of the individual needs of every child.

Emotional well-being:

My family has the support we need to relieve stress.
 My family members have friends or others who provide support.
 My family members have some time to pursue their own interests.
 My family has outside help available to us to take care of special needs of all family members.

Physical/material well-being:

My family gets medical care when needed.
 My family gets dental care when needed.
 My family members have transportation to get to the places they need to be.
 My family has a way to take care of our expenses.
 My family feels safe at home, work, school, and in our neighborhood.

Disability-related support:

My family member with special needs has support to make progress at school or workplace.
 My family member with special needs has support to make progress at home.
 My family member with special needs has support to make friends.
 My family has a good relationship with the service providers who work with our family member with a disability.

long-term outcome – family quality of life – with a common family quality of life measure. This approach to identifying and assessing outcomes could have policy and practice advantages in that it would allow for comparisons across types of supports, services and settings.

Implications for practice

The Beach Center Family Quality of Life Scale and other family outcome measures have multiple potential uses by policy makers, administrators, and practitioners in agencies providing supports and services to families of children with disabilities.

Policy level

Policy makers at the local, state and federal levels could use research results to identify the potential impacts of current policies or policy changes on family quality of life. Quality of life outcomes for families receiving services based on specific policies could be compared before and after changes are implemented. Additionally, quality of life domains and indicators can be used by policy makers to craft new policies designed specifically to address those domains.

Agency and community level

Agency administrators and community work groups could benefit from using family quality of life data to make decisions such as adding to menus of supports and services or staff training needs. Agencies generally are required to report on the outcome or impact of their services to justify continued funding. Quality of life outcome data are an appropriate accountability index for agencies providing supports and services to families.

Individual family level

We are currently developing and testing tools based on the Scale that can be used by families themselves, as well as case managers, direct support staff, and planning teams to identify priority areas for supports and services, as well as areas of strength upon which to build.

Conclusion

Descriptive research on the impacts of children with disabilities on families has traditionally used different conceptualizations of outcomes than intervention research and programme evaluation. We have presented the case for the use of the concept of family quality of life as a unifying construct. It represents an outcome that encompasses disability impacts on fam-

ilies and serves as a long-term impact of services in intervention research and programme evaluation.

The Beach Center Family Quality of Life Scale is a valid, authentic and efficient device for assessing the impact of services on families. Such scales have the potential to serve as an outcome measure at many different levels and may be useful to various stakeholders in research, policy and service sectors who are working to make substantial and sustainable enhancements in the quality of life of families who have children with disabilities.

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