Family Quality of Life and Service Delivery for Families With Adults Who Have Developmental Disabilities

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Abstract

Family quality of life, a major issue for families of adults with developmental disabilities, has been under-examined by researchers. Utilizing interview data previously collected in one geographical region as part of a larger project, this secondary analysis explores service delivery as an important aspect of quality of life for families with adults who have developmental disabilities and are living at home. Employing a modified grounded theory approach, a finer-grained analysis of data from 10 interviews with family members revealed the following themes: (a) obstacles that families encounter when accessing services, (b) concerns about the future, (c) accepting additional responsibility, and (d) unmet service needs. Recommendations for service practice and future research based on the findings from the secondary analysis are discussed.

Family quality of life is an emerging construct in the literature. However, only very recently has this construct begun to be: (a) explicitly noted in the literature, (b) addressed in a systematic, holistic way, and (c) used to guide research studies. Most earlier literature focuses only on one or more separate issues related to quality of life within families. Family stress, family relationships, well-being, health and social inclusion are some of the areas of family quality of life that have been examined separately in the literature (Renwick, Brown, & Raphael, 1998; Brown, Anand, Fung, Isaacs, & Baum, 2003; Park et al., 2003; Posten et al., 2003). Accordingly, the research presented here; (a) acknowledges family quality of life as a construct, and (b) takes a holistic, integrated approach to examining family quality of life and its links with service delivery.

Research utilizing an integrated perspective on family quality of life is significant in that it can yield a clearer, detailed, and more complete understanding of the day-to-day life experiences of families that include adult members with a developmental disability. In their study of quality of life for individuals with intellectual disabilities, McIntyre, Kraemer, Blacher, and Simmerman, (2004) found that supports and resources provided by their families are critical to the well-being of individuals with disabilities and can have a tremendous effect on their quality of life. Conversely, it would seem apparent that the well-being of the person with a developmental disability is both interwoven with, and likely to have a significant impact on, the family's overall quality of life. However, most of the current literature focuses on quality of life of the individual with the disability and not on the quality of life of the family as a whole (Seltzer & Krauss, 2001). Thus, further research is needed to illuminate the nature and experience of family quality of life.

Many complex changes in the area of service delivery for people with developmental disabilities have occurred over the last two decades. These changes have profoundly affected adults with developmental disabilities and their families. The move away from institutional to community living, which involves integrating individuals into the mainstream of community life (Agosta & Melda, 1995) is a notable example. Some recent, noteworthy changes have also emerged in the province of Ontario, Canada, as follows: (a) families and communities are expected to assume increased responsibility in the lives of people with developmental disabilities, while (b) government and service provider's role are to decrease (Brown, Raphael, & Renwick, 1998). In addition, improved nutrition and health care have resulted in a longer life expectancy for individuals with a developmental disability (Campbell & Herge, 2000; Salvatori, Tremblay, & Tryssennar, 2003). Consequently; there is a growing population of adults with developmental disabilities and increasing numbers of aging parents of these adults. Those adults who continue to live at home with their aging parents often experience additional support needs due to the physiological and psychological changes associated with aging (Campbell & Herge, 2000; Freedman & Boyer, 2000). This situation, coupled with the current requirement that families take increased responsibility for their adult child with a disability, may create many challenges and stressors for aging parents. Despite this increasing population of adults with developmental disabilities living at home with aging parents and requiring ongoing care, support, and the use of community services, very little is known about the families' use of, and experiences with, developmental services.

In the province of Ontario there is no central registry of all people with developmental disabilities. The most recent report available on Statistics Canada (2002) data compiled for Canada as a whole in 2001 indicate that there are 120,140 adults (i.e., in the 15 to 64 years category employed in the report). However, the report data for Ontario has acknowledged significant sampling errors and, thus, the report states that these statistics should be used with caution (Statistics Canada, 2002). Further, different definitions for adults (i.e., different chronological ages) and for developmental disability are used by the Statistics Canada (2002) report and by service delivery agencies in Ontario, respectively. Thus, the exact number of adults with developmental disabilities in Ontario remains unknown. Without a clearer understanding of the numbers of adults with developmental disabilities, planning for what people might need, or want, by way of community support services now, or in the future, is difficult (Brown, Percy, & Garcin, 2003). Estimating that 1.5% of the total population has a developmental disability suggests that 110,000 people who are 20 years of age or older might have developmental disabilities in Ontario (Brown, et al., 1998). A 1995 survey of service organizations throughout Ontario reported that approximately 23% of adults with developmental disabilities are associated in some way with service organizations (Brown, et al., 1998). Based on these estimates, approximately 25,300 adults with developmental disabilities utilize services in the province of Ontario, Canada. A comparison of these estimates implies that the number of adults considered as having a developmental disability and those associated with the Ontario service system are quite different (Brown, Percy, et al. 2003).

The focus of service delivery in Ontario has shifted in the past decade. Service delivery now targets enhancement of the individual's quality of life and increasing her/his participation in the community and focuses less on teaching the individual new skills (Campbell & Herge, 2000). Family quality of life has been identified as an important outcome of service delivery for individuals and families' of people with disabilities (Park et al., 2003), yet little work has been done to understand the connections between family quality of life and service delivery.

Several American and Canadian studies have examined service needs and service utilization of caregivers of adults with developmental disabilities (Barnhart, 2001; Brown, Anand, et al., 2003; Campbell & Herge, 2000; Freedman & Boyer, 2000; Heller, 2000; Minnes & Woodford, 2004; Renwick et al., 1998; Salvatori et al., 2003). These have shown that families have unmet service needs, are poorly informed, and need information about resources, programs and services (Barnhart, 2001; Brown, Anand, et al.,

2003; Freedman & Boyer, 2000; Minnes & Woodford, 2004; Salvatori et al., 2003). The published literature available on older parents caring for adults with developmental disabilities has focused on later-life planning (e.g., future living arrangements, financial planning, guardianship, etc.) and indicated that often the main concerns of aging parents are for the future and what is going to happen to their adult child when they are no longer able to meet their child's needs and provide care (Barnhart, 2001; Campbell & Herge, 2003; Heller, 2000; Heller & Factor, 1991).

For two reasons, it is important to link the concept of family quality of life to service provision. First, the nature, content, accessibility, and delivery of developmental and other programs and services can have considerable influence on the quality of life of families that include an adult member with a developmental disability. Second, knowledge about experienced quality of life for these families is needed in order to make beneficial changes to the delivery of services (Renwick et al., 1998). Service delivery that offers minimal constraints and maximal opportunities will likely contribute to the family's quality life. Many of the services that are currently available are being taken away because of a perceived need for financial restraint (Brown, Raphael, et al., 1997), which is likely to have a negative impact on families' quality of life.

In the current context, several key definitions informed the research. *Developmental disability* refers to the service practice definition used in Ontario (Brown, 2003). According to this definition, people with developmental disabilities are those receiving developmental services or on a waiting list for these services. *Service delivery* refers to the provision of professional and/or organization-based services that support the family's needs related to quality of life (e.g., respite care, day programs, vocational support services, etc.). *Optimal family quality of life* is experienced when: (a) a family's needs are met, all members enjoy their life together, and they have the chance to do the things that are important to them and (b) families have relevant opportunities available from which they can make choices to meet their needs (based on Turnbull et al, 2000; McPhail, 1996).

The purpose of this article is to report on the secondary analysis of partial data from a larger study that explored family quality of life. This finer-grained analysis focused on the linkages between service delivery and quality of life for families. The families were all residents of the Greater Toronto Area, in the province of Ontario. The research question examined was, as follows: What aspects of service delivery detract from and contribute to quality of life for families that include adult members with developmental disabilities living at home and receiving community support services?

Research Design and Methodology

The findings presented here represent partial results of a sub-study within the Quality of Life Project (see Figure 1). The Quality of Life Project was a multi-stage research program carried out by researchers from the Quality of Life Research Unit at the Centre for Health Promotion of the University of Toronto. This multi-stage, long-term research program consisted of development of a guiding conceptual framework and measurement instruments used in subsequent cross-sectional and longitudinal studies of quality of life for adults with developmental disabilities living throughout Ontario (Brown, Raphael, et al., 1997; Renwick, Brown, and Raphael, 1994, 2000; Renwick, 2004). When interviews were conducted with the participants who have developmental disabilities, many of their family members asked, "What about our quality of life?" This frequently-posed question led to the development of the Family Quality of Life Project, a qualitative sub-study of the larger research program, aimed at an in-depth investigation of quality of life experienced by a sample of families that included adult members with developmental disabilities living at home (Renwick et al., 1998).

Figure 1. The relationship between this current study and the primary Quality of Life study.
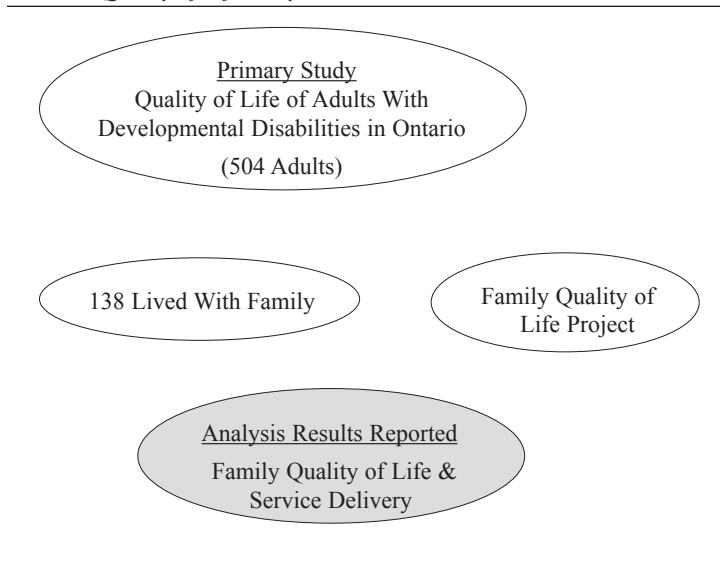
A wealth of data was collected from participating families indicating that family quality of life was a multifaceted construct. Primary, qualitative analysis revealed several key themes associated with family quality of life (Renwick et al., 1998). Service delivery was identified by families as being a particularly important theme related to family quality of life. To investigate the service delivery issues critical to family quality of life, a secondary, finer-grained qualitative analysis was conducted for a portion of the interview data (i.e., for participants in one geographical area) collected for the Family Quality of Life Project. This finer-grained analysis employed modified grounded theory methods, as described by Charmaz (1990). (See the Data Analysis section for details.)

The findings that emerged from this secondary analysis are reported here. Although these data were collected several years ago, the research question at the heart of this study remains to be addressed. The continuing gap in knowledge about family quality of life is amply documented in the foregoing review of the recent literature.

Participants

Interviews for the family Quality of Life Project were completed with 35 Ontario families (25 urban-dwelling and 10 rural-dwelling) that included adults with developmental disabilities, living at home. All participants had an adult family member with developmental disabilities who had participated in the Quality of Life Project. The findings reported here are for analysis of data for 10 participating families living in one geographical region represented in the study, specifically, the Greater Toronto Area (refer to Figure 1). All of these families were, at the time of this study, receiving services from the Ministry of Community and Social Services (MCSS).

Data Collection

The families of the adults who participated in the large-scale Quality of Life Project were contacted by telephone and asked if they would discuss their experiences relating to their family's quality of life. Those who agreed took part in an audio-taped personal interview conducted by a trained interviewer in their homes, in a place that was most convenient for the family. Interviews were from one to two hours in length. All families were interviewed using a semi-structured format, that is, the interview was guided by a series of open-ended questions with follow-up probes designed to explore participants' experiences concerning their family quality of life. See the Appendix for the interview questions and samples of probes employed.

All materials, procedures, and interview questions received ethical approval from the University of Toronto prior to the study. Written and audio-taped informed consent was obtained prior to conducting all interviews.

Data Analysis

In preparation for the analysis, the complete audio-taped interviews were transcribed verbatim to electronic and print formats by two professional transcribers. A modified grounded theory approach was used for data analysis (Charmaz, 1990). To ensure credibility of the data and consistency of the analysis, each author independently reviewed and hand-coded three interviews and then cross-checked the codes that were associated with key themes and sub-themes identified. Credibility in this study was established by the use of an in-depth interview process which constituted prolonged engagement. The dependability and confirmability of the findings that emerged were achieved through the maintenance of systematic records of how data was collected, maintained and prepared for analysis.

Initial codes were identified using a modified grounded-theory approach, which means that coding was not line-by-line. but rather, by means of "data chunks" in order to capture the meanings of the interview passages accurately (Charmaz, 1990). The analysis employed a "constant comparative method of analysis" (Strauss & Corbin, 1990); that is, as the data were coded, each emerging idea or theme was compared with the others within and between interviews to determine whether they agreed or conflicted (Portney & Watkins, 2000). The audio-taped interviews were reviewed and the complete, verbatim transcripts read several times. Throughout this process the coding scheme was continuously revised. The final codes (i.e., labels associated with key themes and sub-themes) agreed upon by the two authors were then employed in the analysis of the verbatim interview data which had already been entered into the software program NVivo (Bazeley, 2007). NVivo was used throughout the analysis phase to facilitate data management as well as online application of codes to the data for the 10 interviews.

Results

Description of Participants

All families had an adult member with a developmental disability who was twenty-years of age or older. With two minor exceptions, the adults with disabilities lived in the family home. There were two minor exceptions: (a) a widowed father whose daughter had very recently moved out of the home

because he was unable to provide for her needs due to his own aging and illness, and (b) an older married couple whose son had just moved to a group home because his mother had serious health problems which prevented his parents from being able to adequately provide for his support needs. However, both of these adults with disabilities continued to return home to spend weekends with the family. The parent or family member who was responsible for providing the principal support and care to the adult member with developmental disability, typically the mother, was interviewed. However, in two families, the father was interviewed. Six out of the 10 families had no father living in the family, either because he was no longer living or had moved out of the family home. In two of the participating families the mother was deceased. The participating mothers ranged in age from 42 to 71 years. Participating fathers were 64 and 70 years old at the time of the interview. Six out of the 10 parents interviewed were 55 years of age or older and the remaining four parents were between 42 and 54 years old. For this portion of the data collected in the original study, the adult family members with developmental disabilities ranged in age from 21 to 42 years at the time of the interviews.

Presentation Format for Qualitative Results

In presenting the findings, several conventions have been followed. The format "…" (three dots) is used to denote words omitted from a participant's quotation and "…." (four dots) is used to indicate an omission between two sentences. In addition, square brackets [ ] are used to indicate that the author inserted a word or words or replaced specific names (e.g., names of hospitals, community agencies, programs) with general terms to protect the anonymity of the place or organization identified in the quotation. To protect confidentiality of all participants, all names used here are pseudonyms.

In reporting the findings, the following terms are employed to indicate the degree to which participants spoke about an experience associated with a theme or sub-theme: (a) "all" families or participants indicates unanimous agreement among all 10 participating families; (b) "most" means eight or nine families out of 10 were in agreement; (c) "some" refers to four, five, six or seven out of 10 families were in agreement; and (d) "a few" denotes one, two, or three families out of 10 agreed. All of the family members with a disability were adults; however, the terms "parent" and "child" are used to indicate the relationship between them.

Major Emergent Themes and Sub-Themes

The finer-grained analysis of the interview transcripts revealed a rich, complex, and integrated picture of family quality of life as experienced by the study participants. The following four major themes emerged: (1) obstacles that families encountered when accessing services for their children with disabilities, (2) future concerns, (3) inability to assume additional responsibility, and (4) unmet family service needs. For each of the following major themes a number of sub-themes were also identified. These sub-themes, along with details of the major themes, are described below and illustrated by personal verbatim quotes from interviewees.

Obstacles Families Encountered When Accessing Services. All of the participants stated that they encountered obstacles of some sort when trying to access community services for their children. Reported obstacles encountered included: lack of coordination of services, lack of information, long waiting lists, and lack of services available to access. All of these obstacles detracted from overall quality of life experienced by their families.

Lack of coordination of services. Some of the families reported a lack of coordination of services. One mother emphasized that there was no organized way to access services:

> *...I didn't even know where to call. I found the hospital was good [when] she was there but...[there was nobody to] be a liaison between the services that were out there and my needs. So I was never hooked up with any groups at all.*

Some of the families noted that, in order to access and utilize the services that were available, they had to be responsible for taking the initiative to coordinate the services themselves. Parents stated that they had to go out and look for services, otherwise their children would never be enrolled in any type of program. One mother said, "… it's up to us to go out and look for things in the community that might fit." In addition, in a few situations, the parents actually took the extra step and established programs for their children to attend, as illustrated by the following quote:

> *...it's part of the parents that we are doing this because in that time it wasn't any program for [the children] and they [would] get very bored at home. They have nothing else to do. So, we think that, OK, we can, you know, arrange some program for them.*

Lack of coordination of services among agencies also posed many challenges to families when they were trying to access services. Families noted that the lack of coordination of services often led to many frustrations and did impact their family quality of life. Some parents suggested that special education teachers should be made aware of the different programs that are available in the community. Then, when needed, teachers could help to coordinate access to community-based support services for children with developmental disabilities. However, as one mother noted: "that's just a pipe dream."

Lack of information. Most of the families reported that they lacked information about how and where to access adequate services. Parents commented that they received information about available services either from other families who had used the services or simply by chance (e.g., when reading the newspaper), rather than through any formal referral programs or information-sharing mechanisms. One parent said, "…when I came out of the hospital, the public health nurse came to visit and then… looked up [and] told me there was an association but couldn't give me any information." An older parent whose son had just recently obtained a place in a group home commented, "…I've not been able to find out if there is a Board [of Directors]…we've let him go there [group home] because we're here to supervise it and…I'm still trying to find out as much as I can about it."

Overall, parents noted the need for better communication concerning the services that are available and related to their needs. Parents stated that they needed help at home with their child but they had no idea where to go or whom to contact for help. Thus, they often never received information and assistance.

It became evident that there were connections among the various sub-themes related to obstacles that families encountered when accessing services (e.g., parents' suggestions regarding the role of the teachers). Parents suggested that elementary and high school teachers should be informed of, and familiar with, the service system so that they could communicate with and inform the parents of the services that are available (i.e., accessible while their children are in school, throughout their transition period from school, and into adulthood).

Waiting lists. A huge obstacle faced by most of the families was the long waiting lists. The father of a 42 year old son with a developmental disability commented that, "there is quite a waiting list to…get [Steven] in a [group

home]. As a matter of fact, I couldn't put [Steven] in one that I want. The waiting list will outlive me."

As a result of these waiting lists parents had little or no choice but to care for their children at home. This meant that they had less time for themselves; to do the things that they needed to do, were expected to do, and wanted to do, which detracted from their own and their family's quality of life. Another parent said,

> *...there's a two-year waiting list even to be evaluated to see whether or not [Susan] can get into it...the people that are in there, why would they leave? They're not gonna leave. They're not making any more spaces, so I guess the only thing is that they move or they get sick or they...they die or something.*

> *Availability of services.* Lack of availability of adequate services also constituted a formidable obstacle for all of the families. It was evident that they faced major challenges as they attempted to find services for their child when he or she finished school and/or reached the age of 21 years. All participants acknowledged that this lack of available services detracted from their experienced family quality of life. An older parent said "I say, every time I turn around, the government or the community services seem to take something away from [Steven] at a time when they should be helping us out more." As another parent put it:

> *....I assume the responsibility for taking [Susan] to any programs that they have....but I can't establish programs. I can only take her places.... [If] there's no place to take her then we're at a dead end.*

Families emphasized the need for more services which are readily available, affordable, and much better coordinated.

Future Concerns

All but two families had their son or daughter living in the family home. The parents' major concerns were optimal future care and future residential placements for their child. One parent, whose son already resides in a group home (but comes home on weekends), expressed her concern in this way:

> *But if we're not here and then [the group home] suddenly decides...[they] don't want to do this anymore. What happens? What happens? Where does he go from there? Will he get into*

something that's of equal quality? Or, will he get into some place where he's behind bars or...as some of these kids are living in?

The parents reflected upon the need for an increased number of high-quality residential facilities. Many parents stated that they just do not know of, or have any information about, such facilities that are available. One single, older father said "he can live, I mean, perhaps a group home would be good…I don't know the workings of them." Another parent expressed her concern about the continuity of her child's future care:

…The group homes don't want kids staying alone all day. They must have a job so…. And whenever she's sick, she tends to get ill for weeks or months at a time. [When] she's in a group home, what's gonna happen to her?...

Many of the parents revealed worries about their own aging and their declining health status. This worry was expressed by one single mother, who stated, "….I still feel that I can [physically lift him], and I can but what about, you know, five years from now?. It worries me. Worries me. But I don't want to think cause I'm scared to think".

The parents specifically worried about what would happen to their children when they could no longer provide for their children's needs or when they were no longer around to do so, or both. Almost all of the older parents also noted what one participant observed: "It's always in your mind. What happens to this child when you're not there to look after him?"

Finally, some of the families had financial worries about their children's future care. One mother said:

I'm struggling to the get the house paid off as fast as I can so that I can start putting money away to help take care of [Susan's] future. You know…family benefits they're…bare meager existence…if that's what [Susan] has to live on. So of course you have to set up one of those trusts, and try and sock as much money…into it as you can so that you can be assured that there'll be something to take care of her…

Inability to Assume Additional Responsibility

Most participants clearly emphasized that their families could not take an increased responsibility for their children, either at present or in the future. Most families stated in very strong terms that they could not take on, or

accept, any more responsibility. One mother responded by saying: "No, absolutely not!" Later on in the interview this same parent described how taking on more responsibility would affect her family's quality of life, as follows:

...it would be a little more stress on me because I would have to give up something of me that I don't have. I mean my whole 100% is gone. So they would be asking for 110% or 115% and I don't have that extra 15 to give.

Another parent's response was: "Our family quality of life would decrease. Definitely decrease. I'd probably have a nervous breakdown." Some parents, particularly the older parents, explained that they could not, and they should not, have to take on any more responsibility than they already do. One parent declared that she could not accept any more responsibility: "I couldn't. Right now. Not at 70…71 years of age. I don't think so." Another single father who had health problems emphasized that he did not have any more time or energy to give. He explained that "…she gets all my time. There's no more to give." He added: "No. I don't have the energy. I hurt too much."

Families' everyday struggles. All participants expressed the belief that every day is a struggle and that they only managed to get by. Many families alluded to the overall strain of raising a child with a developmental disability on their time, energy, and emotions. As one single mother of four children expressed it: "Every day is difficult. Every day is difficult in this family. Because there are so many people tugging at me and me being the only caregiver here [to provide for] the wants and needs."

Lack of discretionary time for self. Most families stated that, in many ways, their lives were limited and they had very little time to do the things that they wanted to do. Most families said that they had no freedom as parents and that it was very hard on them not to be able to do things on the "spur of the moment." Parents noted that in many families with children who do not have disabilities, the children move out of the family home to live their own life, at, or around, the age of twenty years. However, for parents of children with disabilities that is typically not the case. More than half of the participants were aged 55 years or older and still providing support and care for their adult children with developmental disabilities. The parents noted that they wanted the freedom to enjoy the same things in life that most people of their similar age would typically enjoy (e.g., taking vacations, playing golf, engaging in relaxing activities). However, they were often very constrained and unable to do so, because they were still providing partial and/or total care and support, and in some cases, they were doing so

around-the-clock. As one single mother expressed it: "Having Sarah means, uh, I am not flexible now that all my children have grown up…I'm still not able to do the things that I would like to do because I have Sarah." Another parent said that one of the greatest challenges for her family was "…just not being able to do things on the spur of the minute, like, let's go here, let's go there, you...you just don't do it. And you're not…free as parents, as you get older…" Another mother said "I feel like I am a wishbone, I'm being pulled apart in many different directions because each [child] wants a piece of me. And there's so many [children] in this house that there isn't any pieces left for me." Lastly, one single mother summed it up, as follows: "…I'm the one who's mostly with [Christa], just about 98% of the time… things I need to do I sometimes have to give up because of her."

Unmet Service Needs

All but one of the participants indicated that their families' current service needs were not being met. The result was often detrimental and detracted from the quality of life experienced by the family, including the adult members with disabilities. Parents identified several areas of unmet needs. They noted a major need for more in-home parent relief and more readily available respite care on evenings and weekends to provide them with some relief from their daily care-giving demands and struggles. One mother expressed it in the following way:

> *More parent relief…on a weekly turn but also…on a weekly evening basis, or an afternoon basis. More in-home parent relief. and [being] able to get more on a casual…when needed basis… Not having to book months ahead, which I know might be difficult to arrange, but in a more casual form.*

Parents also emphasized the need to have parent support groups, somewhere that they could go and share their feelings and commonalities, without being judged. Last, but not least, parents discussed the need for available mental health counseling for themselves and for other family members. One mother said that her family went through a major grieving stage when their child with a developmental disability was born and she commented that counseling would have added to her family's quality of life and "would have helped both the [older] brother and the father." It would have given them "understanding, acceptance, and sensitivity, you know and dealt with anger on their part."

Participants also discussed the need for more services for their children with disabilities. The services most frequently mentioned were: day programs, employment opportunities, leisure and social activities, life skills training, and transportation services for their child. This requirement for service needs is illustrated by the experiences of several participants, as follows:

> *…there are very, very few day programs available and the ones that are available aren't very good or their spaces are all filled. With very little opportunity for movement. So, I don't know what the future is going to hold.*

> *Like there's no program, there's no great program to say, take these adults bowling one night or to take them swimming one night. There's no support there really at all, that we're aware of.*

> *They [adults with developmental disabilities] need to be more evident in the community. They need to be…more integrated…. They need to be able to have small jobs, where they get paid, and people can see them as being able to perform a function, to be a contributing member of society.*

> *Every[day]…you see another cutback in service …that people can offer and you see places being closed down instead of opening up. You see fewer and fewer opportunities for her to have any kind of a dream.*

Most families spontaneously expressed negative responses to what they viewed as continuous government cutbacks that withdrew services at a time when these were most needed. Cutting these services often left a void for the families affected and changed their lives dramatically, consequently detracting from their overall family quality of life. Families expressed the need for greater and more equitable access to services, as well as the need to be better informed about the options available to them.

Discussion

Due to the shift from institutional to community living, understanding quality of life as experienced by families with members who have developmental disabilities is becoming increasingly important. For example, the Ontario government plans to close all remaining provincially operated institutions for people with developmental disabilities by 2009 (Government of Ontario,

2004). Thus, there are, and will continue to be, increasing numbers of adults with developmental disabilities living at home with their families or in the community and they require many community-based services.

The findings presented here contribute to a better understanding of aspects of service delivery that enhance or detract from quality of life, as experienced by families that include adult members with developmental disabilities. Other Canadian and American studies have investigated separate influences on, or components of family quality of life, such as family stress, family relationships, support from services, long-term planning (e.g., residential placement for adults with disabilities), and health and aging (Brown, Anand, et al., 2003; Freedman & Boyer, 2000; Minnes & Woodford, 2004; Salvatori et al., 2003). These previous findings are generally congruent with the current results. Nevertheless, the current findings are significant in several ways. Taken together, they present a very detailed and powerful depiction of the life these families experience on a day-to-day level. The results offer new insights into family quality of life as it is affected by service delivery. These findings are based on partial data from the first Canadian study to explicitly recognize family quality of life as a distinct concept and to explore it in relation to service delivery, using a holistic or integrated approach. Thus, while other studies (e.g., Chan & Sigafoos, 2001; Salvatori et al., 2003) examine particular aspects of family quality of life, this research adopts a broader and more integrated perspective on family quality of life. As a consequence, the results offer us a view of the 'big picture' of quality of life for these families.

As noted in the Canadian literature, families are expected to assume more responsibility (Brown, Anand, et al., 2003; Brown, Raphael, et al., 1997; Minnes & Woodford, 2004) for the care of their adult family members with disabilities. The findings of this study are congruent but also go beyond these other studies to indicate very strongly that families are overwhelmed with the responsibility of caring for their adult members with developmental disabilities. Further, they could not accept any more responsibility. Responses from the study participants, in particular those families that included older parents (i.e., those 55 years and over) indicate that socially, physically, and emotionally they are exhausted. Furthermore, almost all of the older parents felt that their lives were not their own and they did not have the freedom to enjoy life, the freedom that typically comes from the entry of their adult children into the adult world. Parents do not feel supported to provide care to their adult children with developmental disabilities. A lack of available, accessible, and adequate services (e.g., respite care, day programs, vocational

programs) means that families have few or no opportunities to take breaks from the constant demands and struggles that are involved in providing day-to-day support and care for their adult children with disabilities.

The results of this study clearly suggest that the current community-based developmental services system in Ontario is not meeting the needs of families that are receiving services, at least the ones in this study. As a result of the gaps that exist between service needs and service utilization, these families encountered numerous obstacles when trying to access appropriate and adequate community services for their members with disabilities. These findings are consistent with other research focused on families that include aging adult children with developmental disabilities. Specifically, these families have unmet service needs, encounter many challenges (e.g., issues around funding, lack of information regarding available services, long waiting lists) when accessing services (Barnhart, 2001; Brown, Anand, et al., 2003; Campbell & Herge, 2000; Chan & Sigafoos, 2002; Freedman & Boyer, 2000; Heller & Factor, 1991; Seltzer & Krauss, 2001), and are poorly informed and need more information about services (Barnhart, 2001; Brown, Anand, et al. 2003; Minnes & Woodford, 2004; Renwick et al., 1997a; Salvatori et al., 2003). The current results strongly link obstacles to service delivery and experienced family quality of life. Although families are managing to get by from day to day, their quality of life is definitely compromised by the obstacles that they encounter, and the demands placed on them when they attempt to access needed services and resources. Families indicate that greater, more equitable access to services (e.g., respite care), more easily accessible information about available services, and shorter or no waiting lists for residential facilities would enhance their family quality of life. One of the most critical service issues that parents identified was the need for more respite care. In addition, families emphasize the need for: (a) accessible and affordable day programs for their child, (b) family counseling services, and (c) parent support/education groups for the family. In regard to their adult member with a disability, families perceive the need for: (a) more life skills training, (b) more social and leisure opportunities, and (c) many more vocational opportunities. Other Canadian studies (Minnes & Woodford, 2004; Salvatori et al., 2003) indicated the lack of similar opportunities. Lastly, with regard to services, families felt that they were not well-informed and they were often unhappy with their interactions with professionals. Families expressed many frustrations with the so-called "running around" that they had to do in order to obtain appropriate services. Thus, better-coordinated, more user-friendly, easily accessible, and affordable services would be very helpful and contribute to the families' quality of life.

These families are clearly very worried about the future, which is congruent with past research (Barnhart, 2001; Freedman, Krauss & Seltzer, 1997; Minnes & Woodford, 2004; Pruchno & Patrick, 1999; Salvatori et al., 2003). Parents in this study express serious concern about who would provide care and where their child would live when they (the parents) are no longer alive. They are also very uncertain and anxious about the continuity and consistency of services. In particular they worry that arrangements for future residential care would not endure. Later-life planning involves planning for the future care of children with disabilities including residential, legal, financial, and quality of life issues (Freedman et al.; Heller, 2000; Heller & Factor, 1991; Pruchno & Patrick). However, older parents are often reluctant to participate in later-life planning tasks for reasons such as: (a) it reminds them of their mortality, (b) they are reluctant to relinquish their role and, (c) they often lack adequate information (Heller, 2000). Consequently, it is important for families that include adult members with developmental disabilities to have plans for the future in place to help avoid emergency placements that are unsuitable to both the children and their parents (Barnhart, 2001; Heller, 2000). Parents in this study often thought and worried about future care and placement for their children. However, there is a lack of later-life planning noted by all participants in this study. Parents are fearful and do not want to plan ahead for the future. Parents in this study emphasized the impact of the lack of available residential options for their adult children with developmental disabilities. Without adequate numbers and types of appropriate residential facilities available, families have little or no choice even if they did attempt to plan for the future.

Because this research was guided by a holistic, integrated approach to family quality of life, the findings are able to illuminate the cumulative, collective, and intense impact of a variety of short-comings in the community service-delivery system on quality of life as it is experienced by these families on a day-to-day basis.

Implications for Policy and Practice

All of the families in this study were receiving services funded by the provincial Ministry of Community and Social Services. One important and discouraging finding was the lack of perceived government support (e.g., cutbacks in services) that families frequently encountered. All families emphasized that this lack of support significantly detracted from their experienced quality of family life. Several families noted that changes in government policy have resulted in the reduction of services. Thus, there is a whole segment of the population that is receiving little or no support..

This situation suggests that government policy makers must re-assess the current developmental services system in order to better understand and address the needs of the families. An enhanced understanding of families' current and future needs could help to create better services. Currently, many gaps and barriers remain in the Ontario developmental service system. Consequently, families are unable to adequately access the range and types of services they require.

It was very evident from the results of this study that families are not satisfied with the way in which services are delivered. The families' service needs were much greater than the service opportunities available and accessible to them. Further, the associated difficulties strongly affected their overall quality of life. According to McPhail (1996), whose adult son has a developmental disability, quality of life "includes the availability of options and opportunities from which to make choices and the freedom to make those choices". Therefore, increased availability, more environmental opportunities appropriate to each family's needs, and a better choice of services would certainly contribute to family quality of life.

Limitations

All of the families participating in this study were receiving community-based services. Consequently, the voices of other families were not included. Since this was qualitative research, the results are representative only of the sample of parents who participated. Further, the participants lived in a single geographical region.

Although this study explored family quality of life, only the voices of the main caregivers who were all parents, were reflected in the findings. Thus, our understanding of quality of life that is experienced within each family as a unit needs further expansion. Since the data analyzed were drawn from a larger, cross-sectional study, it was not possible to examine changes in service needs and shifts in family quality of life that may emerge over time.

Future Research

The findings of this study suggest several potentially fruitful areas for future research. Firstly, it cannot be assumed that the voices of just one family member are representative of the views of other family members (e.g., siblings and the adult family member with a developmental disability). According to Posten et al. (2003), examination of family quality of life should consider all family members in determining what is required for them

to have a "good life". Therefore, it will be important for future research to include the voices of other or even all family members in order to gain a comprehensive understanding of quality of life for the family as a whole. Second, the results of this study indicate that accessing services is often a very long, tedious, and frustrating process for families that include adult members with disabilities. When families did utilize appropriate services (e.g., in-home respite care), they reported positive effects on the lives of their adult children with disabilities, and on their families as a whole. However, few families were satisfied with their current situation. Thus, more research is needed to illuminate both the impacts of a lack of appropriate services and the positive effects of service delivery on family quality of life, with the goal of improving both the quantity and quality of the services that these families receive. A longitudinal study would be an ideal approach for examining such issues in the context of the family's service needs and family quality of life over different stages in the life course of the person with developmental disabilities and his/her family.

Conclusion

The findings of this study contribute to the relatively small body of knowledge on family quality of life as a distinct construct. They provide a clearer, broader, and more detailed picture of how having an adult child with a developmental disability affects quality of life experienced by the family. In addition, this research makes a strong link between service provision and family quality of life. Making such a link may inform public policy and other applications that could be of practical benefit to families that include adult members with developmental disabilities living at home. Based on the findings presented, it is clearly evident that the participating families' quality of life has been significantly impacted by several aspects of service delivery. Further, they highlight the need to address the manner in which services are delivered in order to contribute to an improved quality of life for the families who require and utilize these services at two levels, public policy and service delivery. The impact of having an adult with a developmental disability in the family on family quality of life is important now and will continue to be in the future. As the numbers of adults with developmental disabilities living with their families in the community continues to rise, and as parents and family members of this group of adults continue to age, further study of family quality of life in relation to service delivery will be critical. Such research is necessary to help ensure that families receive adequate, appropriate, and efficient services that contribute to their family quality of life.

Appendix
Family Quality of Life Project: Interview Questions

Main Interview Questions

(1) What is good about your family life?
(2) What are some of the things that make life difficult or challenging for your family?
(3) When you first started out as a family, what did you imagine your family life would be like?
(4) What kinds of services or organizations have been most helpful to you in making life good for your family?
(5) What kinds of services or organizations have not been helpful to you in making life good for your family?
(6) Is there anything else that I haven't asked you about your family's quality of life that you feel is important and you would like me to know?
(7) Could you sum up in a few words how good is your family life?

Examples of Probes Employed, as Appropriate

Can you say more about that?
What was that like for you?
How did that affect your family?
How did that make you feel?
Can you give me an example of that?

Authors' Notes

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