

## **Living and Aging with a Developmental Disability: Perspectives of Individuals, Family Members and Service Providers**

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### **Abstract**

*Adults with developmental disabilities are living longer, living in the community, and participating more in society. However, little is known about their day-to-day "lived" experiences and overall quality of life. Using a qualitative research approach, three pilot studies were conducted in two urban centres in Ontario to explore this issue from three perspectives: adults with developmental disabilities, family members, and service providers. Forty-eight volunteers participated in individual interviews or focus group sessions. Preliminary transcript analysis reveals several common underlying themes: social relationships, autonomy, overall life satisfaction, positive changes, health and aging, role of religion, societal attitudes, concerns for the future, and meaningful activity. Important differences existed, however, across the three perspectives. Implications for policy, service delivery and future research are discussed.*

Throughout most of the twentieth century, families were advised to place their children who were born with developmental disabilities in institutions. There was no expectation that they would survive into adulthood, let alone leave the institution or grow old (Grant, 1986; Jones, 1992). Today, however, it is clear that more individuals with developmental disabilities are living longer, living in the community, and participating more actively in all aspects of society. In the last thirty years, the move away from institutional care to community living, along with improved nutrition and health care, has led to an increased life expectancy and thus a growing number of older adults with developmental disabilities (Delorme, 1999; Groeneweg, 1992; Wolf & Wright, 1987). Hammel and Nochajski (2000) suggested that individuals with developmental disabilities comprise between 1.2 and 1.65

percent of the United States population with 526,000 over age 60. Lavin and Doka (1999) estimated that there are 13,000 to 30,000 individuals in Canada over age 60. Additional increases are expected as longevity continues to improve (Boyd, 1997; Janicki, Dalton, Henderson & Davidson, 1999). Living longer means that these individuals will face the same age-related health concerns as people in the general population which, in turn, will result in additional demands on family members, service providers, and society in general (Connolly, 1998; Delorme, 1999; Nochajski, 2000).

Although policy changes in the last fifty years have had a positive impact in terms of deinstitutionalization and community integration for people with developmental disabilities, it is clear that full social inclusion has not yet occurred (Dagnan, Look, Ruddick & Jones, 1995; Donnelly et al., 1996; Janicki & Ansello, 2000; Mahon, Mactavish, Mahon & Searle, 1995; Salvatori, Tremblay, Sandys & Marcaccio, 1998). For example, supported and integrated employment programs are lacking (Murphy & Rogan, 1995; Sandys, 1999), and more options for satisfying leisure activities and retirement programs are needed (Boyd, 1997; Delorme, 1999; Sutton, 1997). Although the concerns of family members tend to increase as their children or siblings age, factors related to the presence of caregiver satisfaction and/or burden remain unclear (Campbell & Herge, 2000; Pruchno, Patrick & Burant, 1996). In their review of Canadian literature, Salvatori et al. (1998) demonstrated the need for: a) more housing alternatives, more employment options, and increased access to community recreation programs; b) more family support and respite services to reduce caregiver burden; c) more assistance for individuals and families with issues related to supported decision-making, legal guardianship, and later-life planning; and d) more individual needs-based planning and services versus program-based planning and services. Brown and Percy (1999) identified similar issues for individuals with developmental disabilities in Ontario. One of the problems with service provision in Canada is that adults with developmental disabilities and their families draw on multiple service systems (health care system, developmental services, services for seniors) which complicates funding, coordination and delivery of services (Salvatori et al., 1998). As Lavin and Doka (1999) have suggested, "the older population with developmental disabilities has been forgotten and neglected, effectively lost in the crack or chasm between systems" (p. 9).

Although more people with developmental disabilities are living longer, living in the community, and participating more in society, relatively little is known about the day-to-day life experiences of Canadian adults with developmental disabilities and their family members. Using a qualitative

research approach, three pilot studies were conducted in the late 1990s in two urban centres in Ontario to begin to explore the "lived" experiences of adults who are living and aging with a developmental disability. The purpose of this paper is to report the preliminary findings of this research and to discuss implications for the future in terms of policy development, service planning and delivery, and further research.

### **Research Design and Methodology**

A qualitative approach was used for this study because it is well-suited to disability research that explores complex phenomena (Barnes, Mercer & Shakespeare, 1999; Llewellyn, 1995). Ethnographic interviews and participant observation are methods commonly used by qualitative researchers to gain information about these populations. Indeed, Mactavish, Mahon and Lutfiyya (2000) suggested that qualitative researchers have an obligation to document and analyze the lived-in experiences of individuals who may otherwise be seen as not having much to offer. Dossa (1992) has specifically discussed the value of narrative discourse as a means of exploring community integration and quality of life issues for people with developmental disabilities. In particular, a life history/oral history approach has been shown to help people with disabilities tell their personal stories and share their life experiences (Goodley, 1996; Phillips, 1990; Tremblay, 1995).

In this study, the investigators chose to use a semi-structured interactive ethnographic interview to explore the life experiences of adults with developmental disabilities from the perspective of individuals, family members, and service providers. The study questions were identified broadly as follows: a) What is life like for adult individuals who are living and aging with a developmental disability? b) What factors enhance or impede social integration and participation in society? c) What is the impact of aging on adults with developmental disabilities and their parents? d) What has been the impact of policy change on the lives of people with developmental disabilities over their lifespan? and e) Do the perspectives of adults with developmental disabilities, family members and service providers differ?

These questions served to guide the interview process; however, because of the iterative nature of the ethnographic interview, the specific format, questions, and probes used differed from interview to interview and also changed over time. As Hammell, Carpenter and Dyck (2000) have pointed out, ethnographic interviews "are informed by the researchers' previous experience...and are shaped situationally by reflecting upon what is being said by the participants" (p.5).

Three sequential pilot studies were conducted over a four-year period. Local self-help consumer groups and community service agencies served as initial contacts to recruit participants. The first pilot study was designed to test out the life history interview approach using a small sample of family members. In order to explore the feasibility of using the same interview approach with adults with developmental disabilities, the second pilot study was conducted using a convenience sample of these individuals. To increase the number of participants, broaden the scope of the study to include the perspective of service providers, and also maximize available resources, the investigators conducted a third pilot study using a combination of two research methods: oral history interviews with adults with developmental disabilities and focus group sessions with family members and service providers.

### **Participants**

A total of 48 persons (17 adults with developmental disabilities, 19 family members, 12 service providers) participated in the three pilot studies. An attempt was made to use a "maximum variation sampling strategy" as described by Patton (1990) to recruit a) adults with developmental disabilities: people of different gender, age, employment status, severity of disability, and type of residential setting (e.g., individuals who lived previously in institutions during part of their childhood and adolescent years and later moved into the community, as well as others who lived at home or in the community throughout their lives); b) family members: fathers, mothers, and siblings; also family members whose relative was receiving full-time residential support as well as those who were receiving respite services only; and c) service providers: both front line and administrative staff of various levels of experience.

Potential participants were contacted and informed of the research protocol. Interview and focus group sessions were set up for all those who agreed to participate, and written consent was obtained. The demographic profiles of participants are outlined in Table 1. In addition to respite services for some families who still cared for their son or daughter on a full-time basis at home, the agency support required by individuals varied from on-call support to 24 hour care. It should also be noted that adults with developmental disabilities were involved in community activities to varying degrees. For example, some participated to a minimal degree such as an occasional outing for a special social event, church service, and/or recreational activity; others were involved on a regular basis two or three times per week doing volunteer work, bowling, or participating in a

retirement program; a few others were working daily in supported employment situations.

*Table 1: Demographic Profile of Study Participants*

<i>Pilot Study</i>	<i>Interview Method</i>	<i>Study Participants</i>	<i>Age</i>	<i>Age of Relative with Disability</i>	<i>Current Residence</i>
#1	individual interviews	7 family members (1 set of parents, 4 mothers, 1 sister)	early 60s to late 70s	26 - 38	3 in family homes, 2 in group homes, 1 in lodging home, 1 in retirement home
#2	individual interviews	5 adults with disability (2 men, 3 women)	47 - 65	n/a	1 in shared house, 1 in family home, 3 in supported apartments
#3	individual interviews	12 adults with disability (8 women, 4 men)	33 - 72	n/a	10 in group homes, 1 in own apartment, 1 in lodging home
	individual interviews & focus groups	12 family members (2 sets of parents, 6 mothers, 2 sisters)	34 - 79	32 - 45	1 in family home, 1 in shared apartment, all others in group homes
	focus groups	12 service providers (9 women, 3 men)	26 - 55	work with adults of all ages	work in various settings

### **Data Gathering**

In the first pilot study, broad open-ended questions were used to guide the interviews with family members (e.g., "tell me about..." the individual's birth and early years, his/her life experiences as an adolescent and adult, the impact of caregiving on the family, the role of siblings, the impact of aging on the individual and the family, their dreams and/or expectations for the future). In the second pilot study, the interview questions were modified for use with adults with developmental disabilities, that is, shortened, more structured, less open-ended, and simplified in terms of language. Based on the difficulty some individuals had with the recollection of past life events, dates and times, the interview questions for adults with developmental disabilities were modified once again in the third pilot study to focus more on current issues and concerns.

Individual interviews in all three studies were conducted in the privacy of the participants' own residences and typically lasted one hour. If requested by an adult with a developmental disability, an agency staff member or service provider was also present. In the third pilot study, focus groups for family members and service providers were all held in a private meeting room at the local public library.

All interviews and focus groups were audiotaped, transcribed, and coded by at least two members of the investigative team to identify key issues and common themes. Initially, participants were given the option of reviewing the transcript of their interview for editing purposes; however, this procedure was discontinued in the third pilot study because little or no editing had been requested by participants in the first two pilot studies.

### **Findings and Discussion**

In the first pilot study, the interviews of family members revealed a broad focus on social justice issues, societal attitudes and the positive changes that occurred as a direct result of their role as "pioneers" in pressuring the Canadian government. In the 1960s and 1970s, many family members had advocated for new programs and services, first for their young children with developmental disabilities, particularly in the area of education programs, and then later on for their adult children in the area of employment and recreation programs. Parents also shared their concerns for the future related to government funding needed to ensure their aging adult children will be able to continue to maintain the lifestyle that they had fought so hard to achieve for them. In the second pilot study, the major issues raised by adults

with developmental disabilities were, not surprisingly, focused on more personal day-to-day "lived" experiences, including the need for more meaningful activity, more positive social relationships, and more personal autonomy. In the third pilot study with adults with developmental disabilities, family members and service providers, similar issues were identified as outlined above; however, three additional themes emerged: health and aging (related to the adult individual as well as aging parents), role of religion, and overall life satisfaction.

Thematic analysis of the transcripts from all three pilot studies revealed nine major themes: social relationships, autonomy, overall life satisfaction, positive changes, health and aging, role of religion, societal attitudes, concerns for the future, and meaningful activity. Although similar concerns were identified by all three participant groups, it is interesting to note that the relative importance of the issues often differed (see Table 2).

*Table 2: Importance of Issues From Three Different Perspectives*

	<i>Adults with Developmental Disabilities</i>	<i>Family Members</i>	<i>Service Providers</i>
<i>Themes</i>			
Social Relationships	X	x	x
Autonomy	X	x	x
Life Satisfaction	X	x	x
Positive Changes		X	x
Health and Aging	x	X	x
Role of Religion	x	X	x
Societal Attitudes	x	X	x
Future Concerns		X	X
Meaningful Activity	x	x	X

*Legend: X indicates an area of major importance; x indicates an area of minor importance*

### **Theme # 1 - Social Relationships**

The importance of social relationships for adults with developmental disabilities was recognized by all three groups of participants; however, few adults with developmental disabilities reported that their relationships with others were entirely satisfactory or rewarding. Individuals consistently identified the need for more social outings and friends, and even intimate

relationships. Some conveyed a sense of loneliness as they discussed the lack of family involvement and the lack of intimate relationships in their lives. Others shared negative memories about their past experiences involving physical and sexual abuse. It is interesting to note that service providers, rather than family members, were concerned about the need for more positive peer relationships for individuals. Family members recognized their role in providing their aging children with important social contacts and relationships, and they were particularly grateful for the relationships their children enjoyed with agency staff; however, they were less concerned about peer relationships.

"Try to understand that people are lonely and all that stuff. My parents don't understand, the staff don't understand." (individual)

" My daughter doesn't make friends easily. She is paranoid and a loner. I am her best friend." (family member)

"You're like family now...more loving and caring because you're much more involved in every aspect of their life." (service provider)

"She [mother] promises she'll come and never shows up." (service provider)

## **Theme # 2 - Autonomy**

All three groups identified the struggle for autonomy for adults with developmental disabilities, that is, achieving a balance along the dependence/independence continuum. Some individuals talked about the need to make their own choices, develop their own sense of identity, be more independent in the community, and live without the interference of family and agency staff. Although service providers recognized the rights of adults with developmental disabilities to make choices and enjoy their privacy, they often identified the wish to protect them, particularly in light of their vulnerability. Service providers also appreciated family interests in this regard. However, they also spoke of the friction that occasionally arises in their relationships with families when there is disagreement as to who decides what is in the best interest of the individual.

"Like we don't want a supervisor...you want to be like those people across the street that live by themselves." (individual)

"You could just see him developing into being his own person." (family member)

"It used to be that we imposed our thoughts on what they needed...now they're voicing what they need...it's a nice shift, very nice." (service provider)

### **Theme # 3 - Life Satisfaction**

It is interesting to note that adults with developmental disabilities expressed little concern regarding the future, probably because of their more concrete orientation to the here-and-now as well as their overall satisfaction with their current lifestyle and living arrangements. Some individuals, however, did express their desire for more money and more vacations in the future.

"I'm happy because I'm living here with another roommate and because I can make more choices for myself like going to my music lessons." (individual)

"Me having money. I like to have stuff. I got money but it isn't enough." (individual)

"I want to have a house with a dog and cats." (individual)

It is also interesting to note that both family members and service providers spoke about how adults with developmental disabilities had contributed to their own sense of life satisfaction. Despite their concerns for their children or siblings and feelings of occasional burden, family members felt fulfilled as caregivers, and service providers identified personal rewards related to their jobs.

"He's been a great joy in our life. I can't say that it's caused too much of a problem." (family member)

"When my son started living on his own, to be an adult...positive change for him and the family too. It kind of took the burden off." (family member)

"I find it very fulfilling for me that I can carry an advocacy role." (service provider)

### **Theme # 4 - Positive Changes**

Although family members and service providers identified the positive changes that have occurred in the last 10 to 20 years in terms of government

policy, programs, and services related to deinstitutionalization and community integration, adults with developmental disabilities had little to say about this issue probably because their concrete orientation to the here-and-now limits their understanding of historical change. It was clearly the older parents who most appreciated these changes because they viewed themselves as pioneers in this regard and were personally involved as advocates in the development of integrated education programs, sheltered workshops, and community living programs.

"The change in their life just by going from a large institution to a small group home is dramatic...like night and day." (family member)

"You don't see as many people acting out aggressively." (service provider)

"Because it's just for the quality of life. It's just more one-on-one and it's just more supportive, medically, mentally, and everything." (individual)

#### **Theme # 5 - Health and Aging**

Many adults with developmental disabilities mentioned numerous health problems; however, most of them were not complaining about deteriorating health or particularly worried about growing older. On the other hand, family members expressed concerns about the health of their aging children as well as their own aging and related issues of caregiver burden. Such concerns were most often identified by those family members who still provided full-time or occasional care for their adult children in the family home. Service providers were also concerned about aging parents.

"If I get old, that's fine with me as long as I have health to do something." (individual)

"Now that we are getting older, we can't manage any more." (family member)

"They are crying out for respite care for these children." (service provider)

#### **Theme # 6 - Role of Religion**

The role of religion emerged as a strong source of support for some individuals, families, and service providers. This was particularly true for

those in this study who were associated with agencies with a religious affiliation such as Christian Horizons, L'Arche, and Beth Tikva, where a strong sense of community is developed. It was also clear that many churches and synagogues are welcoming adults with developmental disabilities to attend religious services as well as various educational and social events.

"I like to get out and spend more time with the people in my church."  
(individual)

"Church is really getting to be a big thing [for adults with developmental disabilities]." (service provider)

### **Theme # 7 - Societal Attitudes**

Although positive changes have occurred in the last two decades, some individuals, family members, and service providers still expressed concern about societal attitudes and the social stigma that remain attached to people with developmental disabilities.

"They said it would be better if I had never been born...that goes in your mind all the way through your life." (individual)

"The thing I remember most is that the children made fun of my son."  
(family member)

"We still come up against barriers but I think the public in general are more aware and see them on a regular basis in grocery stores."  
(service provider)

### **Theme # 8 - Concerns for the Future**

Both family members and service providers remain concerned about the future, especially the need for ongoing government support and funding of programs and services to meet the needs of adults with developmental disabilities and their families. Service providers expressed specific concerns regarding the need for more housing alternatives for older adults, and were particularly disturbed about family members' general lack of concern regarding "permanency planning." For example, families were doing little about planning for the future of their aging child in terms of legal guardianship, residential accommodation and/or economic security. Some parents were avoiding the issue altogether in hopes that their child would die before them.

"If the institution has to close, then where are those kids going to go? No way would our own kids take him home." (family member)

"My biggest wish is that [daughter] goes before I go." (family member)

"We are so dependent on the government...fear of cutbacks leading to poor service." (service provider)

### **Theme # 9 - Meaningful Activity**

Meaningful activity was another common theme. It was clearly service providers who were most concerned about the need for appropriate education opportunities, employment options, leisure and retirement programs, and transportation access. Although all adults with developmental disabilities experienced some form of meaningful activity, most activities were leisure-related.

"I go for walks. I ride my bike. I go to the [retirement] program." (individual)

"He's never ever worked in a place where he is paid real money, like minimum wage." (family member)

"Getting them out of the sheltered workshops and into the mainstream of society where they deserve to be...[with] work that they are capable of doing." (service provider)

It is important to point out that the findings of this study are consistent with other recent work in Canada. A quality of life study conducted in Ontario (Brown, Raphael & Renwick, 1997) involved 504 people with developmental disabilities (19% of whom were 45 years of age or older) drawn randomly from various service organizations in 23 areas across the province. Key findings can be summarized as follows: 1) quality of life is adequate but not good for people with developmental disabilities in Ontario; 2) quality of life is better for people who live independently, with their families, or in small congregate care environments; 3) quality of life is not as good for people who are nonverbal or who have low functional abilities; 4) the number of people who have meaningful occupational activity in community settings is low; and 5) people who live with families appear to have less personal control than might be desired.

Mactavish et al. (2000) conducted a two-year qualitative study in Western Canada to explore social integration issues from the perspective of adults with developmental disabilities. They reported similar concerns regarding the needs of aging adults with developmental disabilities: 1) providing a continuum of services throughout the adult years, including an option for retirement; 2) providing sufficient supports to help adults with developmental disabilities age in place and live in the community with success; 3) responding to changing health needs as individuals age; 4) providing emotional support and grief resolution for older adults who are dealing with the death of their parents and other significant life changes and losses such as changing residence; and 5) providing more respite care for aging caregivers. It is interesting to note that the effectiveness of respite care interventions has been demonstrated recently by Cowen and Reed (2002).

### **Limitations**

Three limitations to the present study are highlighted. First, it is recognized that the opinions and concerns of 17 adults with developmental disabilities cannot represent those of all adults who are living and aging with a developmental disability. Second, a volunteer bias exists in that agency contacts, for the most part, pre-selected potential participants by providing names to the investigators and perhaps limited access to others. Third, since only verbal individuals were interviewed, the perspectives of non-verbal individuals were not represented in this study.

### **Challenges in collecting data**

Using adults with developmental disabilities as participants raised methodological challenges that warrant discussion because there is an ongoing need in the disability literature to try to find the best ways possible to collect information. The investigators first wrestled with the difficulty of developing a consent form using language that would be appropriate and meaningful for individuals, particularly in light of the significant range in intellectual ability. It was necessary, as Stalker (1998) has suggested, to write two separate reports of the findings: one for family members, agencies, and service providers, and another for adults with developmental disabilities with simplified language. It is also possible that many adults with developmental disabilities agreed to participate without fully understanding the purpose of the research, confidentiality of information, and/or potential dissemination of results, although the use of pseudonyms perhaps provided some increased protection in this regard. Rodgers (1999) and Stalker (1998) have both discussed the dilemma of informed consent.

The validity and credibility of information provided by individual participants might also be questioned. For example, it is possible that some adults with developmental disabilities were coached prior to the interviews, perhaps by family members or agency staff. As Matikka and Vesala (1997) have discussed, the problem of acquiescence might have led some participants to say things in order to please the service provider (if present) or the interviewer. Given that adults with developmental disabilities function best within a concrete frame of reference, it is also possible that some of the interviewer's questions were beyond their scope of understanding. For example, one obvious problem was the individual's concept of time, especially in terms of recollecting past events and dates and anticipating the future. In addition, Rodgers (1999) has suggested that having an agency staff member present for an interview with an individual participant is not always helpful. For example, although staff members often supplied specific information for some responses, they were just as likely to jump in too early and answer questions before the individual had an opportunity to do so. Some individuals were distracted during the interview by nearby noises which often resulted in tangential or unrelated comments. Silence was another barrier encountered by the investigators. As Booth and Booth (1996) have discussed, inarticulateness and unresponsiveness are two common challenges related to using narrative methods with people with developmental disabilities, and it may be equally as important to pay attention to what goes unsaid. For example, some individuals became emotionally upset and/or even silent while telling their stories because of negative memories associated with the past (e.g., sexual abuse, marriage breakup, loss of a loved one). Although the potential risk of exploitation in this regard remains a concern, Booth and Booth (1996) remind us that researchers should put more emphasis on overcoming the barriers that impede the involvement of inarticulate subjects in narrative research instead of dwelling on their limitations as informants.

### **Implications for Policy and Practice**

Despite the limitations of this study, the findings have implications for both policy and practice. Policy-makers need to consider expanding residential services to offer a range of housing options on a full-time and part-time basis with varying levels of supervision in order to meet the specific needs of adults with developmental disabilities and provide more support to families. For example, some older adults still living at home with aging parents need to move out, some individuals need a place of their own to live with or without a roommate, some individuals need a setting that provides more

nursing care because of age-related health problems, and some families need more respite support. Limited opportunities for employment, volunteer work, adult education, and recreation programs (especially during retirement) need to be addressed. Service providers need to work closely with individuals and families to promote more independent decision-making and autonomy, to foster more social relationships with peers, to explore the role of religion in the lives of individuals, and to help plan for the future in terms of parental death, legal guardianship, and economic security.

All participants appeared to welcome the opportunity to tell their stories, although it is clear that interviews with adults with developmental disabilities are complex and challenging, and require sophisticated interviewing skills. Despite the challenges encountered, the authors conclude that narrative discourse is a viable research approach, whether the individual interview or focus group format is used. Although similar issues were raised by all three groups of participants, their perspectives are somewhat different and worthy of further exploration; however, additional strategies need to be put in place to address the ethical and methodological issues mentioned above. The use of participant observation as well as informants to validate information obtained from individuals may be costly but worthwhile additions to the methodology for future studies. Ouellette-Kuntz and McCreary (1996) have developed one such tool, the Quality of Life Interview Schedule (QUOLIS), which relies on the use of proxy respondents and participant observation techniques to measure the quality of life for individuals with severe developmental disabilities. In addition, Felce and Perry (1996) have developed an interesting multi-dimensional quality of life model which may serve as a framework for future research in this area.

## **Conclusion**

This paper reported the results of three pilot studies designed to explore the life experiences of adults with developmental disabilities from three different perspectives: individuals themselves, family members, and service providers. The unique contribution of this research to the Canadian literature on aging and developmental disability is its use of qualitative methods. Although participants recognized the positive impact of policy changes in the last few decades that have focused on community integration, it is clear that full social integration has not taken place and negative societal attitudes still persist. Although older adults are living longer and living in the community, their needs are not fully met in terms of social relationships, meaningful activity (education, work, and leisure options), and economic

security. In addition, age-related health issues facing both older adults and their aging parents have contributed to increased caregiver burden and the need for permanency planning. Individuals and family members recognize the support they have received from various agencies, but government policy and services lack specific planning and coordination, especially across government ministries and departments. Furthermore, funding cutbacks in existing services create new worries about future directions. Overall, quality of life issues for adults with developmental disabilities and their families remain an ongoing concern in Canadian society.

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