

Well-being in Aging Parents Caring for an Adult with a Developmental Disability

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Abstract

Given different approaches to service delivery in Canada and the United States and the lack of data available regarding Canadian samples, this study focused on four areas: (a) the major concerns of 80 aging parents of adults with developmental disabilities living in Ontario; (b) their support needs and use; (c) differences in stress and service need and use according to gender, age and whether they lived in urban or rural communities; and (d) the psychological well-being of older parents in relation to stressors, resources and perceptions of stress.

Major issues of concern raised by parents involved long-term planning for accommodation and ongoing emotional and social support, as well as the creation of opportunities for their sons and daughters to participate in activities. Significant differences in service needs and use were found for social and recreational activities, respite care, supported employment, day programs, residential placements, in home support, counselling and behaviour management services. The main reasons given for gaps between service need and use were long waiting lists and a lack of available and appropriate services. Parents reported fewer service needs for themselves than for their family members. Their major needs were for parent support groups and parent education. Predictors of depression in parents included maladaptive behaviour, adverse age-related changes and service use.

With improvements in health care over the past half-century, the life expectancy of individuals with developmental disabilities (DD) has extended considerably. A recent study in Ontario, Canada indicated that 19% of all adults with DD are over the age of 45 years (Brown, Raphael & Renwick, 1997). As a result, the number of older parents providing ongoing care at home for adults with DD is growing (Heller & Factor, 1993). In normative aging, there is a shift of responsibility from parent to offspring. However, as individuals with DD age, they function in increasingly non-normative roles, and older parents of adults report being more stressed and less supported than younger parents (Heller, 1995). As caregivers age, declining health, strength and patience can add to the stress of providing care for adult offspring whose dependency needs will also increase over time (Roberto, 1995).

A number of American, Australian and British studies that have examined the needs of older caregivers have focussed on permanency planning (Bigby, 1996; Grant, 1989; 1990; Heller, 1995; Heller & Factor, 1991, 1993; Smith & Tobin, 1989; Smith, Tobin, & Fullmer, 1995). The range of issues examined includes: who plans and who doesn't; factors related to planning; and the impact of planning on the caregiver and the client. Existing studies focus less attention on how these factors are related to other factors such as caregiver health, psychological well-being, age, and difficulties related to aging.

Other studies, primarily from the US have examined service needs and service use of older caregivers of adults with DD (Lehmann & Roberto, 1995; Caserta, Connelly, Lund & Poulton, 1987; Rinck & Calkins, 1995; Seltzer & Krauss, 1989). It was found that, with the exception of services provided by family doctors, the extent to which services were identified as needed greatly exceeded service utilization. These studies were concerned with the percentage of parents using or in need of various services, but they did not examine how perceptions of stress affect resource use and need, or how resource use is related to caregiver well-being. Research by Seltzer and Krauss (1989) incorporated caregiver well-being (stress, burden, morale and self-rated health) into a study of service use and need and found that unmet service need was a strong predictor of caregiver well-being.

Given the different approaches to service delivery in Canada and the United States and the lack of data available regarding Canadian samples, this study focused on four areas: (a) the major concerns of aging caregivers of adults with DD in Ontario; (b) their support needs and use; (c) differences in stress and service use/ need according to caregiver gender; and (d) potential predictors of psychological well-being of older caregivers of adults with DD including stressors, perceptions of stress and resources.

The Double ABCX Model of family stress and adaptation (McCubbin & Patterson, 1983) has been used in research focusing on the needs of families of children with DD (Cole, 1986; Minnes, 1988) and in research regarding stresses faced by older caregivers (Gats, Bengsten & Blum, 1990). In this study, the ABCX model also was used as a theoretical framework to guide the selection of measures to include as potential predictors of well-being (depression) in older caregivers of adults with DD.

Two types of stressor (A factor) were studied: 1) the characteristics of the adult with DD (maladaptive behaviour) and 2) characteristics of the caregiver (perceptions of health and self perceived advance age change). Resources for coping with stress (B factor) were examined by documenting service needs used and needed by caregivers for themselves and their son or daughter with DD, as well as the availability of different forms of social support. Two variables were included as the C factor: 1) the caregiver's perceptions of stressful issues related to their son or daughter and 2) their ability to view their situation in a positive light (reframing).

Although studies of older caregivers of elderly family members have found that these caregivers are susceptible to depression (see review by Gats, Bengtson & Blum, 1990), studies of stress and coping in older caregivers of adults with DD haven't examined the effects of the double role of aging and caregiving on the psychological well-being of the caregiver. The outcome (X factor) of interest in this study was the well-being of the caregiver as measured by depression.

Research Participants

The sample consisted of 80 parents who were primary caregivers of adults with DD living in urban and rural centres in Eastern and Central Ontario, Canada. Caregivers ranged in age from 50 to 88 years with a mean age of 65.7 years. There were 71 mothers and 9 fathers primarily responsible for the care of their adult child. The majority (62.5%) of these parents were married while 22.5% were widowed and 15% were separated or divorced. Caregivers' level of education was distributed fairly evenly, with 25% having some post-secondary education, 30% having completed high school, and 35% having less than a complete high school education.

The adult family members with developmental disabilities ranged in age from 17 to 59 years, with a mean age of 35.7 years. There were 30 females and 50 males. Their level of disability ranged from mild (27%) to moderate (58%) to severe (15%). Several etiologies were identified, with Down

syndrome being the most common (26%) followed by unknown cause (22.5%), cerebral palsy (12.5%), problems at birth (e.g. lack of oxygen and premature birth) (11%), fragile X syndrome (6%) and autism (6%). The majority (82.5%) of the adults with DD lived with their parents while the other 17.5% lived in community residences.

In order to gather information about how mothers and fathers perceived and responded to caring for their offspring with DD, 21 fathers of adults with DD were interviewed in addition to their wives (who were the primary caregivers). These fathers ranged in age from 50 to 80 years with a mean age of 65.1 years. Thirty-three percent had some post-secondary education, 24% had completed high school and 43% had less than a completed high school education.

Measures

A factor - Stressors

i) Maladaptive Behaviour of the Adult with Developmental Disabilities. The Vineland Adaptive Behaviour Scales - Maladaptive Behaviour Domain, (Sparrow, Bala & Cicchetti, 1984), was used to measure the level of maladaptive behaviour of the adult with DD. This domain of the Vineland consists of 37 statements related to maladaptive behaviour of the person with DD (e.g. Is overly dependent). Each item is rated as 0 - No, Never; 1 - Sometimes or Partially; or 2 - Yes, Usually. The total score ranges from 0 to 74.

ii) Self-perceived Adverse Age-change - Caregiver (Smith, Tobin & Fuller, 1995). This six item scale measures how respondents perceive themselves to be affected adversely by their own aging (e.g. As I get older, it is harder for me to get through the day). Each item is rated from 1 - strongly disagree to 5 - strongly agree. Items are summed for a possible score ranging from 6 to 30.

iii) Caregiver Health Questionnaire (Woodford, 1998). Participants were asked to answer a series of questions about their own health. Questions included: "How would you rate your overall health?" 1 - poor to 4 - excellent; "Have you been hospitalized in the last year? If yes, how many times?"; "How many days have you been unable to perform your normal duties in the last year?" The score on the first question was used as a measure of perceived health. The latter two questions were summed to give an overall health score.

B factor - Resources

i) Checklist of Supports for Individuals with Developmental Disabilities (Woodford , 1998). A checklist of services and supports generated in consultation with parents and service providers was used to measure the number of services and supports used and needed by the adult with DD. Parents were asked to indicate if they knew about these services, whether they needed them, whether they had used them, and if not, why.

ii) Checklist of Supports for Caregivers of Individuals with Developmental Disabilities (Woodford , 1998). A second checklist of services and supports was used to measure the number of services and informal supports used and needed by caregivers for themselves. Services for the caregiver such as Physical Therapy, Nursing, Homecare, and Social Work were included. Once again, caregivers were asked to indicate if they knew about these services, whether they needed them, whether they had used them, and if not, why.

iii) Interpersonal Support Evaluation List (ISEL) (McCull & Skinner, 1995). The ISEL was used to measure the availability of instrumental, informational and emotional support. On this measure, four response options are provided: Never true, sometimes true, usually true and always true. The instrumental support subscale consists of 8 items regarding the availability of practical support (e.g., If I needed someone to drive me to an appointment I could find someone). The informational support subscale consists of 10 items relating to obtaining advice or guidance (e.g., There is someone who can give me advice about money). The emotional support subscale consists of sixteen items regarding understanding, acceptance and friendship (e.g., I have friends I feel very close to). Respondents are asked to indicate the source of each type of support (family, friends and professionals).

C factor - Perceptions of Stress

i) Family Stress and Coping Interview (FSCI) (Nachshen, Woodford & Minnes, 2002). The Family Stress and Coping Interview based upon the Family Stress and Support Questionnaire (FSSQ) (Minnes & Nachshen , 1997) was used to measure perceived stress related to caregiving issues. The FSCI measures the stress reported by parents of individuals with DD in relation to 22 issues including: 1) diagnosis of developmental disability, 2) seeking a second opinion, 3) explaining the disability to others, 4) the cause of disability, 5) day-to-day interactions with others, 6) dealing with health professionals, 7) dealing with legal professionals, 8) education, 9) creating opportunities for family member to make friends and participate in activities

in the community, 10) finding the best level of integration for the family member, 11) decisions about accommodation in the home or the community, 12) meeting the needs of other children in the family, 13) meeting the caregiver's own personal needs, 14) meeting the needs of the caregiver's spouse, 15) maintaining friendships, 16) child's sexuality, 17) work placements, 18) long-term planning for accommodation, 19) wills, trusts, and guardianship, 20) ensuring ongoing emotional and social support for the family member with developmental disability, 21) transportation, 22) assistance with care of the family member, 23) time apart, and 24) financial issues. For each issue, quantitative and qualitative data are collected. There are questions pertaining to the level of stress associated with each issue, availability and helpfulness of support, changes in stress level over time, successes and challenges when dealing with the issue, and changes that could make experiences associated with the issue easier. Each item is rated from 0 - not stressful to 4 - extremely stressful. The sum of these stress ratings results in an overall stress of caregiving score which ranges from 0 to 96.

ii) *F-COPES -Family Crisis-oriented Personal Evaluation Scale (McCubbin, Olson & Larsen, 1981)*. The Reframing subscale of the F-COPES was used to assess whether parents appraise their situation in a positive light as a way of coping.

X factor - Adaptation or Outcome

i) *Depression*. The Centre for Epidemiological Studies-Depression Scale (CES-D) (Radloff, 1977) was used to measure depression. The CES-D is a 20 item scale containing items measuring how the respondent has felt over the last week (e.g. I was bothered by things that usually don't bother me). The possible responses range from 0 - rarely (less than one day) to 3 - most of the time (5-7 days). The total score ranges from 0 to 60.

Procedure

Meetings were held with a number of agencies to solicit participation and to discuss procedures for recruiting participants. Four agencies agreed to participate and additional participants were obtained through Associations for Community Living. The agencies contacted potential participants by mail and used a follow-up phone call to confirm interest in participating and to obtain consent for their names to be passed on to the researcher. Those who agreed to participate in the study were then contacted by the researcher or research assistant to arrange an interview time. On average, interviews

lasted 2-3 hours. In a few instances, interviews were held over two or even three sessions to accommodate the participants' needs. Most interviews took place in the participant's home. In a few cases, another venue was arranged if it was more convenient for the participant. When couples were involved as participants, separate interviews were held in an effort to obtain independent views. Where consent was given, the more detailed portion of interviews regarding the three most stressful issues rated on the FSCI was tape recorded to ensure accuracy and completeness of information.

Results

The following table contains descriptive statistics for the scales used, including the mean, standard deviation (*SD*), maximum value of the scale (*max*), the minimum value of the scale (*min*) and the range of the scores from the participants.

Table 1. Scores on measures

<i>Measure</i>	<i>Mean</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>	<i>Range</i>
Maladaptive Behaviour	13.74	9.04	0	72	0-33
Self-perceived Adverse Age Change	19.79	5.67	6	36	6-29
Caregiver Health	2.78	.85	1	4	3
Interpersonal Support Evaluation List					
Total Score	43.40	8.87	3	63	15-57
Instrumental Support	15.52	4.63		21	3-21
Informational Support	10.26	3.43		15	2-15
Emotional Support	22.36	3.79		27	13-27
Family Stress and Coping Interview	24.78	16.66	0	96	0-64
F-COPES Family- Crisis-Oriented Personal Evaluation Scales					
Reframing	32.71	4.22	29	20	23-40
CES-Depression Inventory	101.62	8.8	0	60	0-33

Stressors (A Factor)

i) Maladaptive Behaviour. Scores on the Vineland Scale for Adaptive Behaviour - Maladaptive Subscale scale ranged from 0 to 33 with a mean of 13.74 (*SD*=9.0). The most common problem behaviour was poor attention

and concentration (71%), followed by overly dependent behaviour (67%), stubborn or sullen behaviour (65%), extreme anxiety (56%), negativistic or defiant behaviour (50%), and withdrawal (46%). Compared to the norms for mentally retarded adults in non-residential facilities, ages 18 years and older (Sparrow, Bella, & Cicchetti, 1984, p. 257), 31 % of the adults with DD were in the non significant range (0-50th percentile) with a score of 0-8. Forty-nine percent were in the intermediate range (51st to 84th percentile) with a score of 9-20 and 20% were in the significant range (85th percentile and above) with scores of 21-39. Non significant scores indicate that the level of maladaptive behaviour is not of particular concern for the individual and no further assessment is necessary. Intermediate scores indicate that further examination of the individual's specific problem behaviours may be warranted. Significant scores indicate that maladaptive behaviour is at a high level and further assessment in this area is needed. Parents who had children with high levels of maladaptive behaviour were asked if they had received any counselling with regards to these difficult behaviours. All of these parents indicated that they had sought support, although some were on waiting lists for services. Others indicated that although there was a need for support to allow their offspring to participate in work or other activities, the funding was not available to allow such support to be put into place.

ii) Self-perceived Adverse Age-Change. The mean score on this scale was 19.79 ($SD=5.67$) with a range of 6 to 29 out of a maximum of 36. The majority (62.5%) of parents reported that they had been adversely affected by age-related changes, while 37.5% had either experienced no change or experienced a positive change.

iii) Perception of Health. On average, parents rated their overall health as good ($M=2.78$, $SD=.85$). The majority of parents (63.8%) rated their overall health as good or excellent while 30% rated their health as fair and 6.3% rated their health as poor.

Resources (B-Factor)

i) Support Needs and Use for Adults with a Developmental Disability. Parents, on average, reported needing 4.92 services and using 2.84 services for their family member. The number of services needed was significantly greater than the number of services used ($t= 8.35$, $p<.0001$) (Table 2). To avoid pairwise error due to multiple comparisons, a conservative significance level was set at $p<0.01$. The most frequently reported needed services were Social and Recreational Services (76%), Case Management (69%), Respite Care (63%), Supported Employment (63%), Day Programs

(58%), and Residential Placement (53%). The most frequently used service was Case Management (63%) followed by Social and Recreational Services (48%) and Respite Care (44%). (Table 2)

Table 2: Supports for Individuals with Developmental Disabilities: Need and Use

<i>Support for Person with DD</i>	<i>% Needing Support</i>	<i>% Using Support</i>	<i>T</i>	<i>p</i>
Social/Recreational Activities	76%	48%	4.34	0.001*
Case Management	69%	63%	2.06	0.044
Respite Care	63%	44%	4.28	0.001*
Supported Employment	63%	29%	4.90	0.001*
Day Program	58%	32%	5.31	0.001*
Residential Placement	53%	15%	6.89	0.001*
In - home support	36%	22%	3.03	0.004*
Counselling	28%	11%	3.62	0.001*
Behavioral Support	22%	6%	3.74	0.001*

iii) Support Needs and Use for Parents. On average, parents reported needing 2.23 services and using 0.80 services for themselves. The number of services needed were significantly greater than the number of services used ($t=7.13, p<.001$).

Table 3. Support for Parents: Need and Use

<i>Support for Person with DD</i>	<i>% Needing Support</i>	<i>% Using Support</i>	<i>t</i>	<i>p</i>
Parent Support Groups	63%	20%	5.82	0.001*
Parent Education	35%	5%	7.64	0.001*
Homemaker	24%	14%	2.57	0.013
Physical Therapy	23%	16%	1.66	0.103
Nursing Care	12%	7%	1.76	0.083
Counselling	11%	2%	2.32	0.024
Psychology	7%	2%	1.43	0.159
Social Work	7%	2%	1.76	0.083

Once again, a conservative significance level was set at $p<0.01$ to avoid pairwise error due to multiple comparisons,. The number of parents reporting a need for service was relatively small. The largest number of parents reported a need for parent support groups (35%) and parent education (25%). The most frequently given reason for not using parent support groups was

"not aware of the service" (34%) followed by "no access to service" (17%), "service not available" (17%) and "service not appropriate" (17%). A large percentage of respondents not using parent education indicated that they were not aware of such a service (56%). "Lack of time" (20%) and "service not appropriate" (12%) also were frequent responses. The primary reasons given related to parent support groups and parent education being inappropriate for the respondents in this study were transportation to parent support groups and the focus on the needs of young as opposed to older families.

C Factor - Perception of Stressors

The mean score on the FSCI was 24.79 ($SD=16.6$) with a maximum score of 96. Not all issues were identified by parents as being of concern, however, between 50% and 83% of parents identified 8 of the following issues as stressful (i.e., mean stress score >2.5): long term planning for accommodation (83%), planning for emotional and social support (68%), creating opportunities for their child to participate in activities and make friends (56%), meeting their own personal needs (55%), making decisions about accommodation in the home or the community (54%), time apart from their family member with a developmental disability (51%), planning for wills, trusts and guardianship, (50%) and dealing with health professionals (50%).

Adaptation or Outcome (X Factor)

i) Depression. The mean score on the CES-D was 10.16 ($SD=8.8$) out of a maximum score of 60, which is within the normal range for community based samples of adults (Murrell, Himmelfarb, & Wright, 1983). Sixteen percent of the parents obtained scores above the cutoff (20) for clinical significance which is comparable to the norms of 14% for men and 18% for women within this age range.

Preliminary Analyses

Note: Due to multiple comparisons, the significance level was set at $p<.01$.

ii) Mothers versus Fathers. When both parents were interviewed there were no significant differences ($p<.01$) between mothers and fathers on any of the measures used in this study.

iii) Parents Living in Rural versus Urban Communities. The sample was divided into parents living in urban and rural centres. There were no significant differences between rural and urban dwellers on any of the measures used in this study.

e) *Multiple Regression Analysis: Predictors of Depression.* Several correlations were computed among the major variables in this study. Due to the relatively limited sample size, only variables that were highly correlated were chosen to be included in a multiple regression equation to determine predictors of depression.

A hierarchical multiple regression analysis was conducted with scores on the CES-D as the dependent variable. Based on preliminary correlation analyses, five independent variables were included in the equation. Three variables were entered in the first block as A-factor Stressors: 1) Vineland Maladaptive Behaviour Subscale scores, 2) caregiver adverse age changes and 3) caregiver overall health. One variable was entered in the second block from the C-Factor (Perceptions of Stress: FSCI total score), and two variables were entered as the B-Factor resources (ISEL Instrumental Support subscale score and Service Use for Family Member with DD total score). Two variables representing the A factor emerged in this analysis as significant predictors of depression: Maladaptive behaviour ($p < .05$) and Caregiver adverse age changes ($p < .03$). These variables were positively correlated with depression. In addition, one variable representing the B factor: Service use for the person with a developmental disability was negatively correlated with depression and emerged as a significant predictor. ($p < .03$).

Table 4. Hierarchical Multiple Regression: Predictors of Depression

Predictors of Depression	B	Std. Error	Beta	T	P
(Constant)	4.224	7.401		.571	.570
Maladaptive Behaviour	.196	.097	.221	2.009	.049*
Adverse Age Changes	.434	.195	.274	2.231	.030*
Overall Health	-1.673	1.222	-.175	-1.370	.176
FSCI Total	3.664 E-02	.057	.073	.644	.522
Service Use for Person with DD	-.159	.072	-.238	-2.202	.032*
Instrumental Support	2.124 E-02	.034	.078	.632	.530

$R = .588$ $R^2 = .346$

Discussion

Aging parents already provide the majority of care for their adult children with DD. However, as the average lifespan of persons with DD continues to increase, and as the demand for community-based residential options for

persons with DD exceeds availability with the closure of institutions, more parents will be caring for their offspring into their seventies, eighties and beyond. This research has documented some of the unique stresses and needs of a sample of Canadian parents. The results are similar to those of American studies which highlight major concerns regarding accommodation, future support and guardianship as well as the need for a number of formal supports in the community (Freedman, Griffiths, Krauss & Seltzer, 1999).

The primary caregivers participating in this study ranged in age from 50 to 80 years with a mean age of 65.7 years. Contrary to expectation, older parents of adults with DD (over the age of 65 years) were not found to perceive caregiving as more stressful than younger parents (between the ages of 50 and 65 years). Previous studies have suggested that this may be due to parents' ability to adapt to caregiving stress over time (Seltzer & Krauss, 1989; Townsend, Noekler, Diemling & Bass, 1989). In this study it appears that all parents of adults with DD shared many common concerns regardless of age. This finding suggests that many issues noted as stressful for parents are chronic stressors that need to be reassessed and managed at intervals. Both younger and older parents of adults are faced with difficult transition periods (Wikler, 1986) and associated challenges such as longterm planning, transportation, and creating opportunities for an individual with DD to make friends and participate in activities throughout their adulthood.

Recent studies of mothers and fathers of individuals with disabilities have shown that the experiences of one parent may be highly related to those of the other (Dyson, 1997). Differences which do occur may reflect differential roles and caregiving responsibilities (Minnes, 1988). In this study, there were no significant differences in the responses of mothers and fathers on the FSCI. This finding may reflect more equal involvement of parents in the caregiving, especially after retirement. There were also no significant differences in caregiving stress reported by parents from urban or rural settings. This finding may be related to general concerns regarding access to services and supports regardless of the distance to be travelled.

Of the 24 issues discussed with parents, 3 were reported by more than half of the parents as being particularly stressful. Long-term planning for accommodation was the issue of greatest concern regardless of the family member with DD's current place of residence. This finding is supported by American research on permanency planning (Heller & Factor, 1991, 1993; Smith, Majesky, & McClenny, 1996) which has indicated that this is the greatest worry for parents of adults with DD. In this study, long-term planning for accommodation was found to be stressful for 84% of parents.

Almost half (37) of the primary caregivers reported a need for such accommodation and many were frustrated with long waiting lists for community residences. Many respondents referred to the problem of individuals from institutions with funding being given priority for community placements over their family members. They felt that they were being penalized for keeping their family members in the community for so many years. Other parents (19%), indicated that they had simply given up trying to find appropriate accommodation for their son or daughter. Some parents were hoping that their other children might take over responsibility for their son or daughter when they die. However, such arrangements were problematic for many parents for a variety of reasons: because their other children worked, because the children lived far away, or because their child's spouse was less willing to take on the handicapped son's or daughter's care. The parents that had found accommodation outside the home for their son or daughter with DD were generally satisfied with the placements, although several had to go out of their community to find a space. The families whose sons or daughters with DD were living away from their home community found the distance difficult and stressful.

The emphasis in the literature on permanency planning as a key issue for older parents would suggest that if family members with DD were living in the community and not in their family home, parents would experience less caregiving stress. However, the results of studies of the impact of residential placement are unclear (Baker & Blacher, 2002). The results of this study support those of McDermott, Valentine, Anderson, Gallup & Thompson, (1997) who found no significant differences in concerns between families of adults with DD living at home or living in community residences.

Planning for the emotional and social support of their family member with DD was also a stressful issue for 64% of parents, including those whose sons or daughters were no longer living at home. This particular issue has not been addressed in the literature, perhaps because it is less concrete than planning for accommodation. After many years of care, while some parents may be overprotective, many have a strong, inter-dependent relationship with their offspring, as well as a strong sense of responsibility and/or guilt (Smith & Tobin, 1989). In this study, most parents felt that their son or daughter would never receive the care that they received at home if they went elsewhere to live. Parents felt that this issue was difficult to resolve, but that consistency in care from other sources, through improved working conditions and better wages in service agencies and opportunities for offspring to make friends outside of the family would help to decrease their concerns.

A major concern for parents was whether their child would receive adequate care from people other than themselves. Parents were worried about the ability of their other children to care for their child with a developmental disability. As well, many parents were concerned about their child's emotional well-being in a group home. The parents interviewed had been the primary caregiver for their children for their whole lives. These parents often strongly identified with their caregiving role, and found it emotionally difficult to relinquish that role.

Similar to the findings of Heller and Factor (1991), creating opportunities for their family member to make friends and participate in activities was a concern of for 56% of the parents interviewed in this study. Parents whose family members were successfully participating in day programs or activities stated that they didn't know what they would do without these programs. However, many other parents had experienced program closure or a loss of appropriate programs as their children aged.

Predictors of Depression in Older Caregivers

On average, parents' scores on the depression measure were within the normal range for the age group. However, 16% of parents obtained scores above the cutoff for clinical depression. Two stressors: maladaptive behaviour and adverse age changes (representing the A factor) and Service Use (representing the B factor) emerged as significant predictors of depression. Maladaptive behaviour and adverse age changes were positively correlated with depression, whereas service use was negatively correlated with depression. Although the total stress score from the Family Stress and Coping Interview was significantly correlated with depression and adverse age changes, this variable representing the C factor in the ABCX model did not emerge as a significant predictor of depression.

Significant amounts of maladaptive behaviour have been found to be associated with high levels of caregiving stress in previous research (Minnes, 1988; Westling, 1996). Similarly, In the present study, total stress score was significantly correlated with maladaptive behaviour. Heller and Factor (1993) found that maladaptive behaviour was a strong predictor of increased caregiving burden. Maladaptive behaviour was also found to be associated with increased difficulty in permanency planning because it was less likely that the parents could depend on other family members to take on the responsibility of caring for the adult with DD. In the present study, 69% of the individuals with DD were reported by parents to have moderate to severe maladaptive behaviours. The most common problems were poor

attention/concentration, dependency, stubbornness, negativistic or defiant behaviour, anxiety and withdrawal. Some parents of adults with high levels of maladaptive behaviour reported that there was little time or energy for dealing with any other issues beyond day-to-day needs. Several parents reported that, as their son's or daughter's maladaptive behaviour increased, their ability to participate in community activities decreased, necessitating parents to take on more responsibility for their needs. This increased responsibility led to isolation from social and formal support. Although 22% of parents indicated the need for behaviour management support for their son or daughter, only 6 % were using such services. When asked why they were not using behaviour management services, 50% of parents reported that they were not aware of such services. Other parents who had used the service were either not satisfied with the support received (14%) or disagreed with the approaches used /felt that they were not appropriate for their son or daughter (22%). Other parents indicated that they did not have enough time or did not feel able to carry out the role of mediator (7%).

The majority of parents (62.5%) reported that they had been adversely affected by age-related changes. However, the mean score on this scale was 19.79 ($SD=5.67$) which is within the mid-range. Nevertheless, higher reported adverse age changes were significantly correlated with depression. Smith et al. (1996) also found adverse perception of aging to be associated with increased subjective burden. Parents who are aging and possibly depressed may well feel less able to deal with maladaptive behaviour that may have been present and tolerated for some time. These findings highlight the need to increase both caregivers' and service providers' awareness of the effects of aging. Older parents, however, should not be treated as a single group. Parents' perceptions of adverse age changes, need to be considered as opposed to merely chronological age.

In addition to characteristics of the family member with a developmental disability and characteristics of the caregiver, Service Use for the family member (representing the B factor), which was negatively correlated with depression, also emerged as a significant predictor. Past research with caregivers of individuals with various disabilities (e.g., Stephens, Norris, Kinney, Ritchie, & Grotz, 1988) has found that escape-avoidance coping predicted depression, whereas, problem- focused coping has been found to be associated with lower depression scores. For parents participating in this study, service use appears to have had a protective effect. In this context, service use may be seen as a form of problem-focused or active coping (Lazarus & Folkman, 1984). Since this variable represents the sum of services used, it is not possible to determine whether the use of particular

services contributed to well-being or whether merely being linked to services provided parents with sufficient support to fend off depression. Previous research by Engelhart, Brubaker & Lutzer (1988) suggests that caregiver assessments of their current ability to provide care is related to the amount of service use. If parents are depressed and have lower self esteem and less confidence or sense of mastery, they may well feel the need for more support. This is an important area for further research.

Conclusion

The results of this study support past research and provide new insights into the experiences of older parents caring for an adult son or daughter with a developmental disability in Ontario. The quantitative and qualitative data gathered reflect a number of important concerns of parents from the age of 50 onward. They reveal significant discrepancies between the need and use of services and supports, and demonstrate that parents experience ongoing concerns for the welfare of their children with a developmental disability whether children live at home or in the community. Results also highlight the relationships between maladaptive behaviour, adverse age-related changes, service use and depression.

At the end of each interview, parents were asked for their suggestions about ways to improve services and supports for parents. The recommendations of parents, summarized below, were remarkably consistent. Parents' recommendations regarding long term accommodation included more readily available information regarding accommodation options. They also recommend an increase in the quantity of group homes available (so that the parents could plan appropriately) and improvement in the quality of these homes. In particular they recommend the establishment of permanent homes set up for less than four individuals where residents and staff remain constant and there is a more family-like environment (i.e., less structure) and a higher standard of living. A change in legislation to allow parents to leave their homes to their child without it affecting their disability pensions was also suggested. Several parents also requested more opportunities to have their sons or daughters live in a family setting. The parents stressed the importance of planning ahead so that their family member would not have to deal with the stress of losing his/her parent(s) and relocation at the same time. Parents also recommended more day programs for senior citizens with DD and more in-home care or readily available respite care to facilitate the gradual transition to other caregivers and settings in the community. Parents also wanted more help from agencies, such as emotional support, skills training, and respite care to help keep their adult child at home as long as possible.

Although it is generally assumed that support from professionals and service agencies is beneficial for families of individuals with DD, interactions may add to parental stress rather than reducing it (Baxter, 1987). A recent Canadian survey of barriers to residential planning (Joffres, 2002) suggests that a history of difficult relationships with service providers and a history of unsatisfactory services may contribute to parents' general mistrust of services and a reluctance to seek support from service agencies in the public sector. Further research is needed to explore the impact of relationships between parents and service providers on parents' service use and planning.

In addition, the need for information was a common theme throughout our interviews with parents. A recent survey of service providers in Ontario (Sparks, Temple, Springer, & Stoddart, 2000) highlighted the need for more training and information on aging for professionals and paid service providers. For example, 61% of respondents reported that they did not feel adequately trained to deal with issues of aging and developmental disability. Given a history of mistrust and disappointment on the part of parents and the need for more training on the part of paid care providers, one strategy may be to develop information and training programs designed for both family and paid caregivers. An approach which taps into the life long experiences of older parents as well as the insights of paid caregivers could have multiple benefits, not the least of which would be to develop positive working relationships and help to facilitate parent and professional/ service provider partnerships (Turnbull & Turnbull, 1986)

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