Centre on
AGING
UNIVERSITY OF VICTORIA

INFORMAL CAREGIVERS TO CHILDREN WITH DISABILITIES
IN
BRITISH COLUMBIA

Report of the

CENTRE ON AGING,
UNIVERSITY OF VICTORIA

CAREGIVERS ASSOCIATION OF BRITISH COLUMBIA

and the

RESPITE ADVISORY COMMITTEE,
B.C. MINISTRY OF HEALTH

February, 1995

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The research was conducted and report written by investigators:

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- The generous financial support of the Seniors Independence Program of Health Canada, in the form of a grant to do a comprehensive telephone survey to identify Caregivers to Adults and to do community follow up activities.

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The Caregivers Association of B.C. and the Centre on Aging gratefully acknowledge the financial contributions of both the federal and provincial governments in this much needed undertaking.

This report provides:

- An overview of the findings obtained from a survey of caregiving to children with disabilities. A separate report documents findings for caregiving to adults. For further information about or analyses of these data, contact the Centre on Aging, University of Victoria. A cost may be assessed.

- **Characteristics of Caregivers to Children**
  - ▸ Caregivers tend to be women (primarily mothers), younger or middle aged, married and living with a spouse as well as others.
  - ▸ Over 60% of the caregivers are employed in the workforce.
  - ▸ Many of those who are not working say they would rather be working.

- **Nature and Extent of Caregiving**
  - ▸ Caregivers in B.C. provide much support to children in need of care. Many have been providing care for many years (average 6.6 years), for many hours each day. The types of care provided include assistance with personal care activities, household tasks, education, leisure and social activities, transportation, etc.
  - ▸ Caregivers receive help from both formal and informal sources and the number of individuals involved in caregiving is greater than frequently thought. The vast majority (90.9%) report that one or more additional caregivers are involved. Most can name another informal source whom they feel would look after the child if they couldn't.

- **Caregivers' Needs**
  - ▸ Over three-quarters of the caregivers interviewed found caregiving stressful. The vast majority (93.4%) thought they were coping well, however. Caregivers were more likely to report poor emotional than physical health.
  - ▸ The biggest rewards were having a positive impact and being able to help.

- **Characteristics of Children Receiving Care**
  - ▸ Children receiving care are somewhat more likely to be male than female. Most are under 12 years of age.
  - ▸ Most have multiple health problems, with the most frequent being learning disabilities, developmental delays, and attention deficit disorders.

- **Utilization of Services**
    - Most caregivers are aware of most of the government services but use few.
    - The most widely used services are: therapy services, medical equipment or supplies in the home, recreation, and special needs day care.
    - For most services, professionals assume a major role in arranging for services. However, caregivers are also prevalent in arranging for services, particularly in accessing day care, recreation, and specially trained sitters.

- **Comparison of Caregiving to Children and Adults**
    - Caregivers to both children and adults are largely women. For children, the caregivers are predominantly mothers; for adults, caregivers are primarily spouses or daughters.
    - Caregiving to both children and adults is extensive and both tend to receive support from informal and formal sources.
    - The majority of caregivers to both children and adults found caregiving to be stressful. However, the proportion reporting stress was somewhat greater among caregivers to children. Both also report rewards associated with the role.
    - The characteristics of children and adults receiving care are different. Children are somewhat more likely to be male, adults tend to be female. For both, a multiplicity of health problems is evident. However, the types of health problems involved differ.
    - Service utilization patterns are similar despite differences in the types of services used. Relatively few services are used.

- **Conclusion**
    - For many families, caregiving is a reality of day-to-day living. In these times when many women are working, many are also providing care. They provide care with empathy and concern within a network of others in order to assist the care recipient. They are coping, but it is a balancing act with both rewards and difficulties.

Table of Contents

List of Tables

List of Figures

CAREGIVERS TO CHILDREN WITH DISABILITIES IN BRITISH COLUMBIA

Introduction

Informal caregivers, including family members, friends and neighbours provide the majority of care to children and adults of all ages requiring ongoing care and support due to long-term physical or mental health or behavioural problems. It is only recently, however, that widespread public and government recognition has been directed to the important role that caregivers play in providing health care and support to children and adults with long-term illnesses and disabilities. Indeed, informal caregiving has now become a cornerstone in the rhetoric for health reform in virtually all provinces. British Columbia is no exception (Province of British Columbia, 1991). With concerns over increasing costs and possible over-medicalization of the health care system, the recognition of informal caregivers is embraced as a key element of community care.

Despite this recognition and an abundance of research documenting the important role played by caregivers, little information is available about the actual numbers of caregivers, who they are caring for and what services they are receiving. Research on caregiving to those in younger age groups is particularly lacking (Kahana, Biegel and Wykle, 1994). In British Columbia, for example, little is known regarding how many caregivers there are, where they live in the province, their age and gender distributions, or what their needs are. There is an urgent need for such information, particularly in light of the recognition of informal caregivers within current health care reform and the requirement for newly formed health regions to provide respite through home-based services.

To obtain this information, the Centre on Aging at the University of Victoria undertook a province-wide survey, in conjunction with the Caregivers Association of British Columbia, funded through the Seniors Independence Program and the Respite Care Committee of the B.C. Ministry of Health, and generous in-kind support from the Continuing Care Division, B.C. Ministry of Health. Several individuals contributed to the design of the questionnaire, including members of the Ministries of Health and Social Services, the Caregivers Association of B.C. Board, and caregivers themselves.

This report presents the results of that survey. A brief discussion of the literature and description of the methodology used is presented, followed by a discussion of the prevalence of caregiving to children and adults with disabilities in B.C. The characteristics of caregivers to children with long-term illnesses and disabilities are outlined and their needs and characteristics of the children they care for provided. A discussion of service utilization follows.

What We Know About Caregiving

There are only a limited number of studies available that establish prevalence rates for caregiving. In the United States, a national study conducted by the American Association of Retired Persons (AARP) and the Travellers Companies Foundation Survey (1989) found almost 8% of all households contained a caregiver. Caregivers were defined as persons who provided unpaid assistance, for either two instrumental activities of daily living, or one basic activity of daily living, to a person 50 years of age or older within 12 months of the time of the interview (Biegel et al., 1991).

A household survey conducted in the United Kingdom (1985), a country with a greater proportion of older adults, estimated 1 in 7 (14%) were carers. Their study used a general question which asked: "Some people have extra family responsibilities because they look after someone who is sick, handicapped or elderly. May I check, is there anyone living with you who is sick, handicapped or elderly, whom you look after or give special help to (for example, a sick or handicapped or elderly relative/husband/wife/child/friend, etc.)?" They also asked: "And how about people not living with you, do you provide some regular service or help for any sick, handicapped or elderly relative, friend or neighbour not living with you?"

In 1991, a national survey conducted in Canada (the Ageing and Independence Survey) asked Canadians aged 45 and over: "Which of the following are major activities in your life at this time - working for pay or profit?; managing a home or being a homemaker?; taking care of a family member or close friend?; doing volunteer work?; or something else?" According to this study, 12.7% of Canadians aged 45 and over named caregiving (i.e. taking care of a family member or friend) as a major activity. Looking at only the B.C. population in this survey, 14.3% of those aged 45 and over listed caregiving as a major activity.

We know from existing research that informal caregivers are more likely to be women than men, and that for children, parents, particularly mothers are most likely to be the caregivers. Grandparents, aunts, uncles, and other family members and friends are also involved.

Research generally has shown only recent interest in employed caregivers, no doubt spurred by the increase in the number of women who have returned to paid labour. While this

Figure I

British Columbia

Health Units

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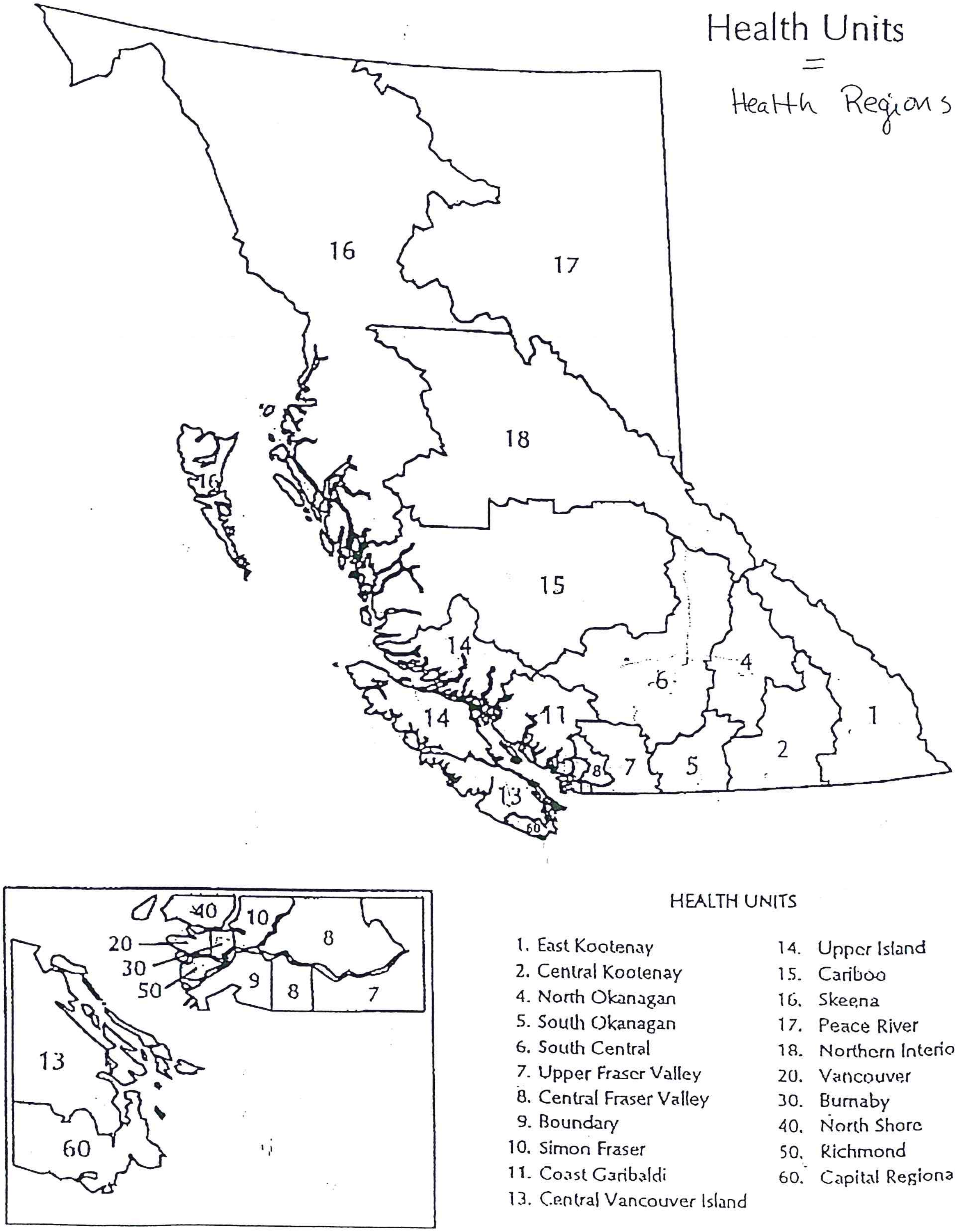
Health Regions



HEALTH UNITS

1. East Kootenay
2. Central Kootenay
4. North Okanagan
5. South Okanagan
6. South Central
7. Upper Fraser Valley
8. Central Fraser Valley
9. Boundary
10. Simon Fraser
11. Coast Garibaldi
13. Central Vancouver Island
14. Upper Island
15. Cariboo
16. Skeena
17. Peace River
18. Northern Interior
20. Vancouver
30. Burnaby
40. North Shore
50. Richmond
60. Capital Regional District

Prepared by: Health Economics & Planning Branch, Ministry of Health & Ministry Responsible for Seniors
Map Source: CSB, Ministry of Finance & Corporate Relations

APR93

population aged 50 and over (Biegel et al., 1991). The population figure is, however, lower than the figure reported by the Canadian Ageing and Independence Survey. This likely reflects the fact this latter survey referred only to those caregivers aged 45 and older. In contrast, the current study refers to all adults aged 19 years of age or older.

The remainder of this report examines caregivers to children. A separate report deals with caregivers to adults.

Characteristics of Caregivers to Children

Gender and Age

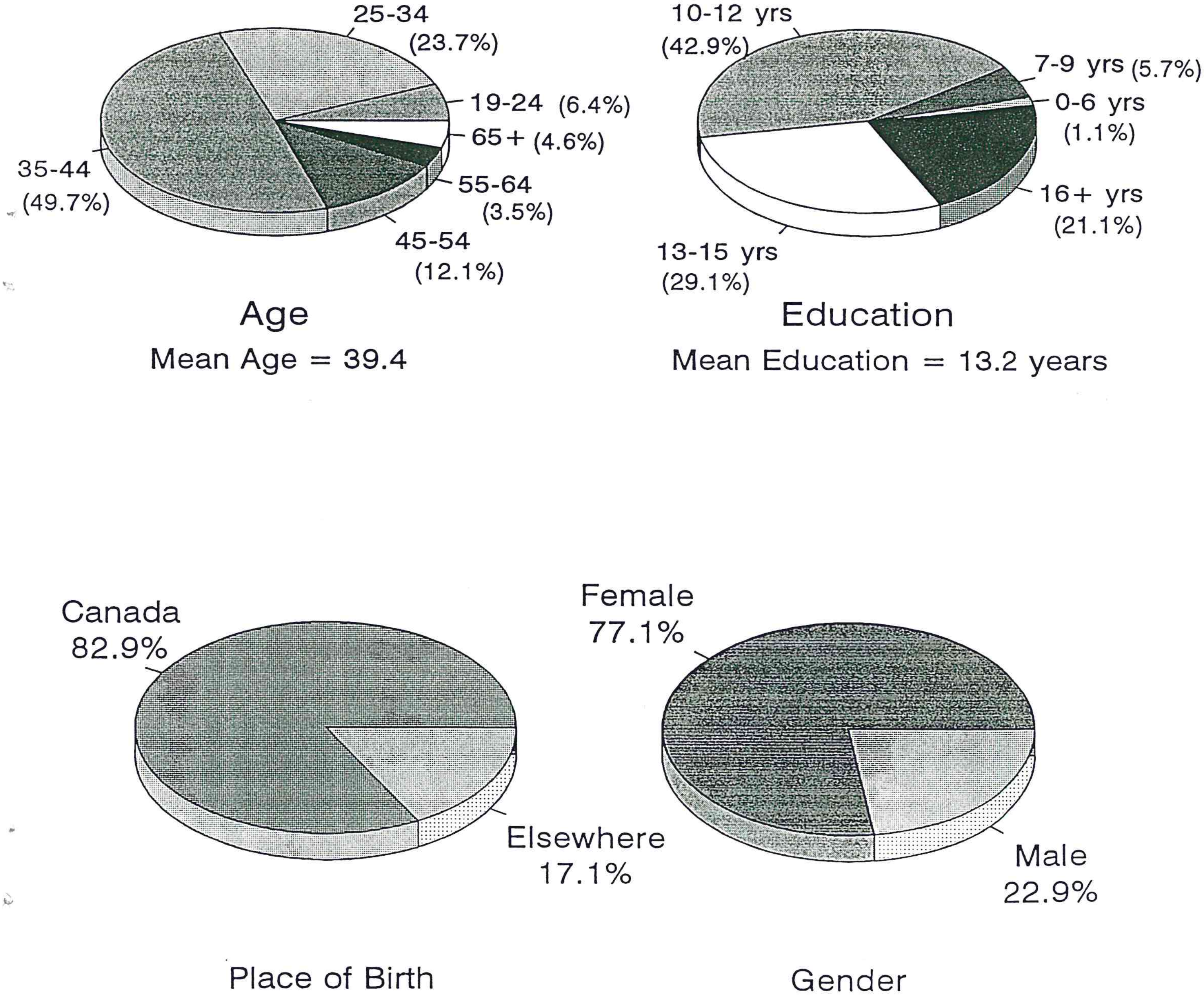
Traditionally, the majority of caregiving responsibilities for children have been assumed by women, particularly mothers. Approximately one-half of the adult population (aged 20 and over) of the province is male (48.9%) and one-half is female (51.1%) (Statistics Canada, 1993). However, over three-quarters (77.1%) of the caregivers to children with disabilities in this study are women. Sixty-nine percent (69.5%) of the caregivers are parents of the child receiving care. The majority of these (76.9%) are mothers, the remainder are fathers (23.1%). The caregivers' ages range from 19 to 80. The average age is 39. Almost one-half (49.7%) are in the age group 35 to 44 years of age, with 30.1% aged 19 to 34 and 20.2% aged 45 and older. In contrast, within the adult population of the province as a whole, 22.6% are 35 to 44, 32.6% are 20 to 34, and 44.7% are 45 and above (Statistics Canada, 1993) (see Figure 2).

Education, Place of birth language, ethnicity

The average number of years of schooling reported by the caregivers who were interviewed was 13.2, and one-half of the respondents (50.3%) had 13 or more years of schooling. This

Figure 2

Caregiver Background Characteristics



is comparable to figures for the adult population of the province as a whole (Statistics Canada, 1993). The vast majority (82.9%) of caregivers were Canadian born and listed English as the language they preferred to speak (92.5%). Just over one-third (34.3%) viewed themselves as Canadian. Forty percent (40.7%) said they had no ethnic self-identification, and the remainder stated they were English (6.4%) or reported some other ethnic identity (18.6%).

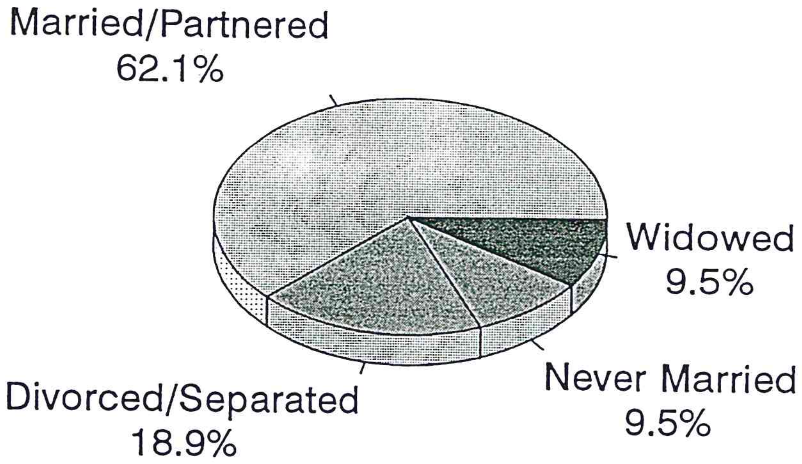
Marital status and Household size

There is debate in the literature on caregiving regarding the impact of having a chronically ill child on the stability of the marital relationship. Some contend that the stress associated with caring for a child with special needs often leads to marital difficulties and divorce (Conman and Kaestner, 1992; Mauldon, 1992) whereas others suggest marital relationships and family cohesion may be strengthened by the experience (Yuna and Darling, 1987). In this study, most caregivers to children reported being married or involved in common-law or other partnerships (67.4%) (see Figure 3). However, twenty percent (20.5%) were separated or divorced, 10.3% were single, and 1.7% were widowed. In 1991, among the adult population (aged 20 and over) of B.C. as a whole, a similar proportion (69.0%) were married, fewer (8.5%) were divorced or separated, and more (18.5%) were single or widowed (6.6%) (Statistics Canada, 1993).

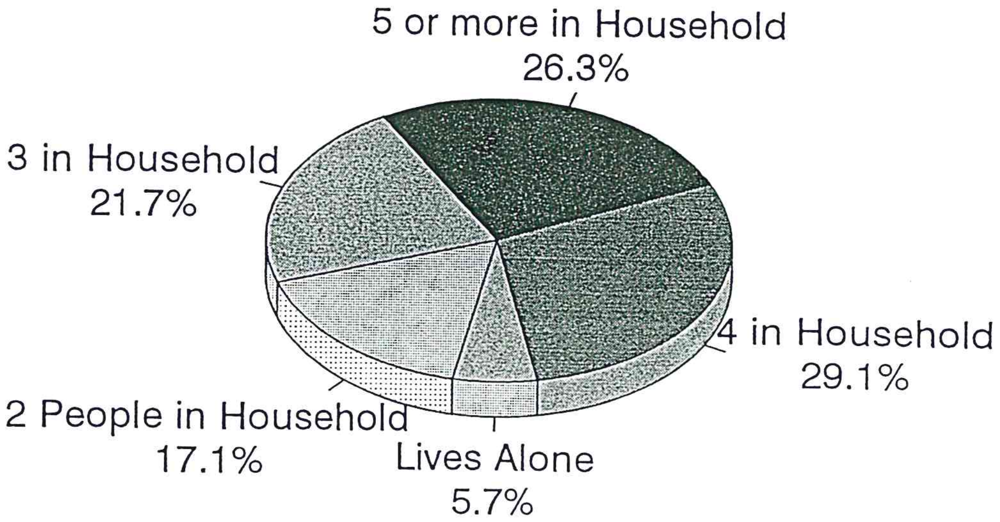
Relatively few (5.7%) caregivers reported living alone, reflecting the fact that most were married. The average number of residents living within the households of caregivers to children was 3.6. This is larger than the average household size (2.6) for the province as a whole (Statistics Canada, 1991). Looking more

Figure 3

Caregivers' Social Characteristics



Marital Status



Size of Household

Mean Household Size = 3.6

closely at the composition of the household, we find that 49.7% of the caregivers lived in two-parent families with children, one of whom was the child receiving care. Somewhat fewer (14.8%) lived in single-parent families with one or more children, one of whom was receiving care. The vast majority of these families (84.6%) were headed by women.

Employment

In June, 1994, 68.3% of adults in British Columbia were employed (Statistics Canada, 1995). In this study, most (61.5%) caregivers to children were employed in the paid labour force, and over sixty percent (66.1%) of those who worked did so more than 30 hours per week. They could therefore be considered to be employed full-time. Those who were employed worked from 3 to more than 90 hours per week, with an average of 33.9 hours (see Figure 4). Almost two-thirds (63.3%) of those who were not employed indicated that they would prefer to be employed.

When caregivers who had quit working were asked why they had quit, 33.3% said they quit work in order to provide care either as their first or second reason for quitting. Those currently working reported a variety of impacts on their work lives. Over forty percent reported that they had to leave work to take the care recipient to the doctor (43.8%) or had to miss work due to caregiving responsibilities (43.8%) (see Table 2). Over one-third (36.1%) felt their performance had been affected; 38.2% have had to leave work suddenly; 34.0% had come to work late; and 33.3% had decreased the number of hours they worked. Others reported having changed work shifts due to caregiving (29.9%); getting frequently interrupted while at work (25.0%); changing jobs (15.3%); and declining job advancements (14.6%).

Figure 4

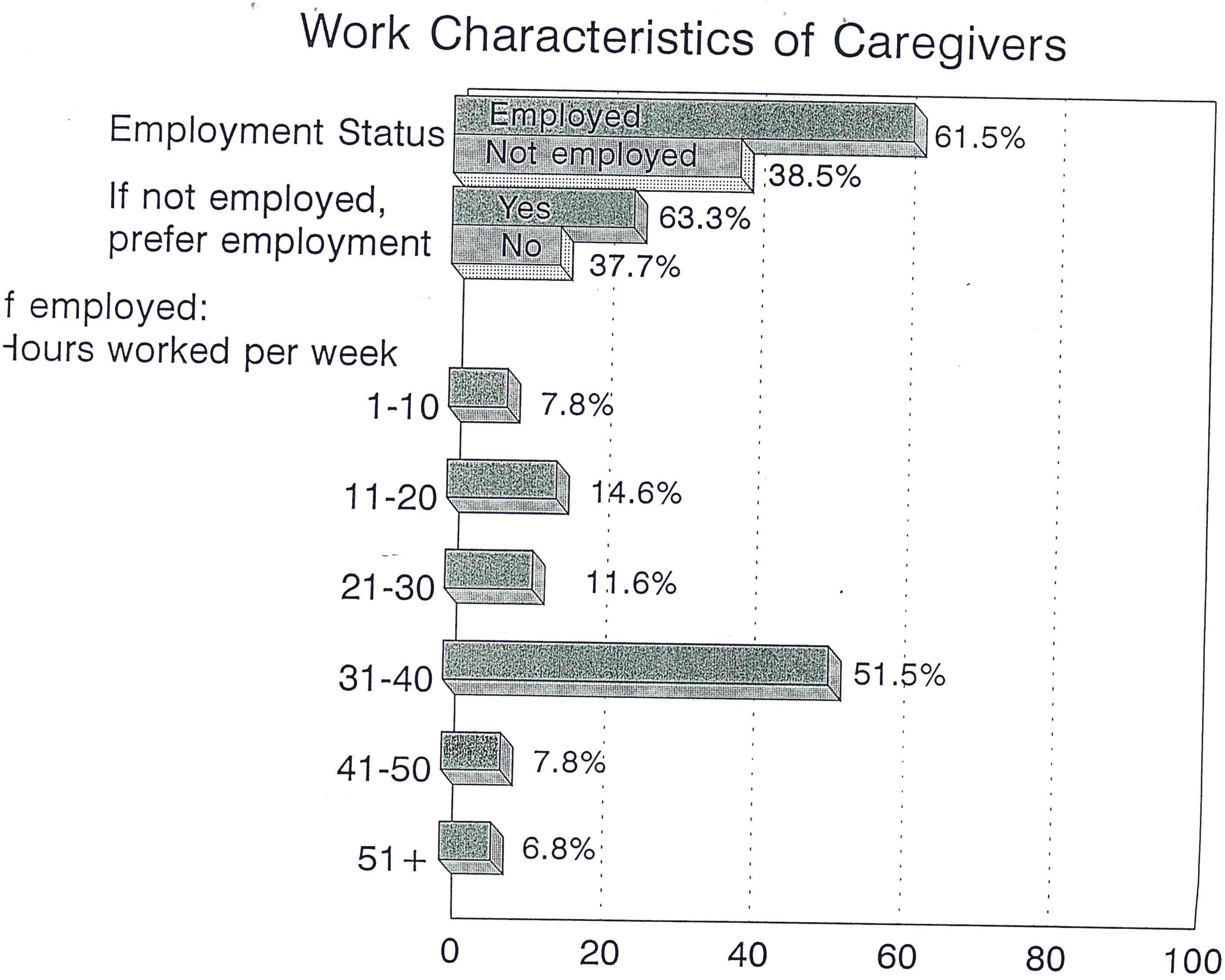

Work Characteristics of Caregivers
Employment Status
Employed
61.5%
Not employed
38.5%
If not employed, prefer employment
Yes
63.3%
No
37.7%
f employed: Hours worked per week
1-10
7.8%
11-20
14.6%
21-30
11.6%
31-40
51.5%
41-50
7.8%
51 +
6.8%
0
20
40
60
80
100

Table 2
Impact of Caregiving on Work

Left work for doctor's appointment	43.8%
Missed work	43.8%
Left work suddenly	38.2%
Felt performance affected	36.1%
Come late to work	34.0%
Decreased hours worked	33.3%
Changed shift	29.9%
Getting interrupted at work	25.0%
Consider quitting work	19.4%
Changed jobs	15.3%
Declined job advancement	14.6%
Increased hours worked (e.g.,to earn more money)	6.3%

Summary

In sum, caregivers to children with long-term illnesses and disabilities in B.C. tend to be women. They tend to be younger to middle-aged adults who are married and live with their spouse as well as others. A significant minority (32.5%) are not married however, with a somewhat greater proportion being divorced or separated than is true of the adult population of the province generally. Whether this is tied to caregiving is not known. Many caregivers work and many of them work full-time. In many ways, these characteristics reflect those of Canadians within the population as a whole.

Nature and Extent of Caregiving

Primary and Secondary Caregivers

Most of the research on caregiving focuses on the primary caregiver. It is often assumed that there is primarily one caregiver. This study purposely selected caregivers to participate in the study without regard to the nature and extent of the actual caregiving tasks in which they were involved. This allows us to distinguish between primary and secondary caregivers, and to draw a more complete picture of caregiving responsibilities. In this study, almost two-thirds (63.4%) of those interviewed reported they were the primary caregiver involved with a particular child (see Table 3). The vast majority (90.9%), however, also said that they received help with caregiving tasks. This help could be from either formal or informal sources.

Table 3
Nature of Caregiving

Consider Self Primary Caregiver	
Yes	63.4%
No	36.6%
Does Anyone Help You (asked of everyone)	
Yes	90.9%
No	9.1%
No. of Caregivers (including respondent and both formal and informal caregivers)	
1	9.8%
2	39.9%
3	22.5%
4	27.8%

Among those who reported receiving help, the most frequently cited sources of help were a parent or parents of the child (80.5%), grandparents (21.4%), paid/formal caregivers (20.8%), siblings (15.1%) and aunts or uncles (13.8%). The average number of caregivers reported to be providing care for

Table 4
Extent of Care Provided

How long have you provided care for ( )?	
≤ 1 year	15.4%
≤ 2 years	13.1%
≤ 5 years	22.9%
≤ 10 years	24.0%
> 10 years	24.6%

Hours of care	
≤ 1 hour/day	10.8%
2-4 hours/day	31.8%
5-7 hours/day	10.1%
8+ hours/day	47.3%

Frequency of care	
< once/week	7.9%
1-6 times/week	14.6%
7+ times/week	77.4%

day; and 27.3% of men and 56.5% of women put in 7 or more hours per day ($\chi^2 = 11.2$; d.f. $= 2$; $p < .01$). Interestingly, there is no gender difference in terms of whether or not the primary caregiver has assistance from others, and there is no gender difference in terms of who that help comes from.

Types of Care

The types of care provided by caregivers include help with personal care activities such as walking, dressing, bathing and eating; instrumental activities such as housework, shopping, meal preparation and getting to places outside of walking distance; as well as activities like education, learning communication skills, physical therapy, administering medications, and assisting with leisure and social activities.

In this study, caregivers of children aged 6 and over were asked whether they provide help with personal care activities such as taking care of their appearance, bathing, dressing, eating, walking and using the toilet. Almost one-half reported providing help with taking care of the child's appearance (49.5%) and dressing (47.4%). Somewhat fewer provided assistance with bathing (42.1%), eating (39.8%), using the telephone (30.7%), using the bathroom (26.7%), walking (22.4%), and getting in or out of bed (18.1%). However, for <u>those children who needed help</u> in each of these areas, the vast majority of caregivers reported providing assistance. Thus, among children needing help with dressing, 95.6% of the caregivers interviewed reported providing help. This was also the case when needs were evident with regard to eating (94.7%), taking care of one's appearance (86.5%) using the bathroom (84.6%) and so forth (see Table 5).

Caregivers of children aged 12 and over were also asked whether they assisted the child with housework, meal preparation, shopping and other such instrumental activities. Over one-half of those caregivers interviewed reported providing help in most areas. Once again, when the child involved needed help in a given area, the vast number of caregivers tended to report that they themselves provided such help (see Table 5).

The majority of caregivers to children of all ages also reported providing assistance to the child with such things as learning communication skills (80.5%), educational activities such as help with reading (77.3%), leisure or social activities (73.6%), and transportation (69.9%). Somewhat fewer reported providing

Table 5
Type of Care Provided

	Total Sample	Only Children In Need of Help
Children aged 6 and over:		
Eating	39.8%	94.7%
Dressing	47.4%	95.6%
Taking care of appearance	49.5%	86.5%
Walking	22.4%	78.3%
Getting in/out of bed	18.1%	76.5%
Bathing	42.1%	83.0%
Using the bathroom	26.7%	84.6%
Using the telephone	30.7%	61.9%
Children aged 12 and over:		
Getting places out of walking distance	57.1%	96.3%
Shopping	58.3%	86.2%
Preparing own meals	58.0%	83.9%
Participating in housework	53.1%	80.6%
Taking medicine	56.5%	85.7%
Managing own money	58.3%	83.3%
Children of all ages:		
Education (eg., help with reading)	77.3%	---
Learning communication skills	80.5%	---
Physical therapy	34.7%	---
Leisure/social activities	73.6%	---
Transportation	69.9%	---
Administering medications	48.9%	---
Managing health care technologies	28.9%	---

help with administering medications (48.9%), physical therapy (34.7%), or managing health care technologies (28.9%).

Who Would Take Over?

Caregivers were asked who would take over if they could no longer provide the care required. Most (85.5%) named another informal caregiver, 11.0% named no one or said they did not know who would provide care; and 3.5% referred to a paid caregiver or formal service provider. Among those stating someone would take over, parents of the child were the most likely alternative caregivers to be mentioned first (59.0%). They were followed by grandparents (10.3%), aunts and uncles (9.6%) and siblings or other relatives (7.7%).

Summary

Overall, these data show that caregivers in British Columbia provide extensive support to the children they are providing care for. There is variability, but on the whole many of these caregivers have been providing care for several years, and they do so for many hours a week. While most are primary caregivers, nevertheless they do receive help from both formal and informal sources. Furthermore, should they no longer be able to continue with their caregiving activities, the vast majority are able to name another informal source who would look after the care receiver. These findings confirm and are a testament to the strength and viability of the informal network within our society.

Caregivers' Needs

Stress and Coping

Literature in the area of caregiving tends to focus on the stress or burden of caregiving, with very little written on the rewards of this particular role (George and Gwyther, 1986;

Montgomery, 1989). We asked the caregivers whether they found caregiving stressful. Over three-quarters said they did (77.7%), with no significant difference between men and women in the proportion reporting being stressed (see Table 6). Those who said that they were stressed were also asked if they felt the stress constantly or intermittently. Over one-half of those reporting stress (58.1%) said it was intermittent, with 41.9% saying it was constant. Those who said they found caregiving stressful were also asked if this stress was moderate, extreme, or both. Approximately one-half said that it was both (53.7%), sometimes moderate and sometimes extreme. Over one-third (36.0%) said it was moderate, with a minority saying it was extreme (10.3%). Caregivers were also asked how well they thought they were coping. The vast majority (93.1%) thought they were coping well.That is, most are stressed but most also feel they are coping.

Table 6
Rewards and Stresses of Caregiving

a)	Describing Caregiving	
	Not stressful	22.3%
	Stressful	77.7%
	If stressed,	
	Intermittent	58.1%
	Constant	41.9%
	If stressed,	
	Moderate	36.0%
	Sometimes moderate/extreme	53.7%
	Extreme	10.3%
b)	Coping	
	Well	93.1%
	Not well	6.9%

Placement Outside of Home

Caregivers were also asked whether they thought it might ever be necessary to place the child receiving care in a residence outside the home. Approximately nineteen percent (18.6%) of the caregivers interviewed stated that this had already been necessary or might be necessary at some point in the future. Of those who thought it might be necessary, almost one-third (32.3%) stated they were considering placement in the near future. The reasons given for considering placement included the child's health problems (43.5%), the caregivers' own health problems (17.4%), and the difficulties of providing the care required (25.9%).

Well-being

When caregivers were asked about their subjective well-being, the majority stated that they considered themselves in good physical and emotional health and saw their health as similar to last year (see Table 7). However, a substantial minority felt that their physical health (20.6%) and their emotional health (28.0%) were fair or poor and a similar number reported that their health was worse now than it was a year ago (18.9% and 17.1% for physical and emotional health, respectively). It should be noted that a greater proportion of caregivers felt they were in poor emotional than poor physical health.

Difficulties in Caregiving

Caregivers were asked whether they were under a financial strain as a result of caregiving, whether caregiving interfered with their ability to meet the needs of others in their household, as well as what they felt had been the most difficult part of caregiving. Almost one-half (45.1%) of the caregivers reported experiencing at least some financial strain as a result of caregiving. As well, almost two-thirds (64.5%) of those living in the same household of independence, frustration and so forth). Fewer responses centered on having to deal with formal organizations (6.4%) or on specific problems of the child, such as their deafness, behavioural problems, or mood swings (5.2%). Another 8.1% centered on the child's loss of freedom or privacy. Only 5.8% of the caregivers said there was nothing difficult about caregiving.

Table 8
Difficulties and Rewards of Caregiving

Most difficult part of caregiving.	
Other caregiver centered concerns (feel helpless, deal with mortality, guilt, accept child's illness, family conflict, lack of help)	32.0%
Seeing child suffer (lose independence, feel depressed, frustrated, unable to enjoy things)	27.3%
Dealing with formal organizations	14.5%
Caregiver loss of freedom/privacy	8.1%
Nothing	5.8%
Specific are receiver problems (deafness, behaviour mood swings)	5.2%
Other	14.5%

Most rewarding part of caregiving.	
Impact on child	45.9%
Relationship with child	25.3%
Being able to help	12.9%
Other	12.3%
Nothing	3.5%

Rewards of Caregiving

Caregivers were also asked about the rewards of caregiving, an area rarely investigated in the literature. Few (3.5%) could name nothing that was rewarding. Over one-half (58.8%) referred to their positive impact on the child (45.9%) or to simply being able to help (12.9%). Others (25.3%) referred to the personal relationship with the child (such as the closeness of the relationship, feelings of gratitude and friendship).

Summary

This information on caregivers' needs suggests that, on the one hand, they feel they are coping, and yet on the other hand, they feel stresses and experience difficulties. Interestingly, caregivers were somewhat more likely to report being in poorer emotional than physical health. The tremendous concern of the caregiver for the child comes through when they are asked about the rewards and the difficulties involved. Many talk about their own feelings in coping with what the care recipient is experiencing, the helplessness and so on. The rewards also focus on personal feelings and relationships, especially with the person they are caring for and being able to help that person. These data point to the emotional level and the relationship level as areas of prime importance if we want to relate to caregivers. Caregivers' needs are very human needs. It is in this area that we should be providing assistance, perhaps in the form of support groups or other programs with an emotional component.

Characteristics of Children Receiving Care

Gender and Age

In 1986-87, 5.2% of Canadian children under the age of 15 had a disability of some type. This rate was somewhat higher for boys (5.7%) than for girls (4.7%) and was highest among boys aged 5 to 9 (7.3%) years of age (Health and Welfare Canada, 1990). In the current study, over one-half (58.3%) of the children receiving care were male. They ranged in age from infancy to 18 years of age. Their average age was 8.9 years with two-thirds (66.9%) under 12 years of age (see Figure 5).

Relationships

In terms of the relationship of the child to the caregiver, child care recipients were most likely to be a son (42.5%), or a daughter (27.0%). Overall, close relatives (children or siblings) made up 71.3% of the child care recipients. Other relatives (nieces, nephews, grandchildren, etc.) made up 16.5% and friends and others made up 12.1% (see Table 9).

Table 9
Relationship of Child to Caregiver

Son/stepson	42.5%
Daughter/stepdaughter	27.0%
Other Relative (niece, nephew cousin, grandchild, etc.)	16.5%
Non-Relative	12.1%
Sibling	1.7%

Health

According to the Canadian Health and Activities Limitations Survey (Health and Welfare Canada, 1990), the most prevalent long-term health problems or disabilities among children in British Columbia, in order of prevalence, include: learning disabilities, intellectual disabilities, heart conditions or disease, diabetes, cerebral palsy, arthritis or rheumatism, epilepsy, kidney conditions, paralysis, and lung conditions. Further, about 1 in 6 children in B.C. with a disability have a hearing problem and about 1 in 7 of those with a disability have a vision problem not correctable by using glasses.

In the current study, the children receiving care needed such care for a variety of health reasons. They had an average of 3.6 chronic physical conditions. Only 13.1% of the children had either no or only one long-term physical health problem. The average number of physical and mental health and behavioural problems reported was 4.9. Only 7.4% had only one long-term physical or mental health or behavioural problem. As shown in Table 10, care receiving children suffered from a variety of conditions: 59.5% had learning disabilities; 47.1% were developmentally delayed; 36.4% had attention deficit disorders; 33.3% were hyperactive; and 24.0% had respiratory problems. The main conditions cited by the caregivers as being responsible for the child's need for care were developmental disorders (24.1%) cerebral disorders (23.4%) and cancer (10.6%). For most (56.6%), their most serious illness or condition began at birth.

Table 11 shows the percentage of children needing help with various tasks. Among those aged 6 or over, at least one-third of the children needed at least some help with: eating, dressing, grooming, bathing, and using the telephone. From 6.8% (for eating) to 19.7% (for using the telephone) were completely unable to do such activities. In terms of walking, 21.7% were unable to walk without help or supervision: 11.3% relied on personal assistance only, 5.2% relied on a wheelchair either instead or in addition to personal assistance; and 5.2% were classified as completely unable to walk.

Among children aged 12 to 19, approximately one-half (46.5% to 53.8%) needed some level of help with activities such

Table 10
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Learning disability	59.5%
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Bowel or urinary problems	21.1%
Visual impairment not relieved by glasses (eg. blindness, cataracts, glaucoma)	19.1%
Severe allergies	17.1%
Epilepsy	16.1%
Hearing loss	15.0%
Heart & circulation (cardiovascular problems)	14.6%
Cerebral palsy	12.6%
Undetermined diagnosis	11.0%
Other mental handicap	11.0%
Other behavioral/emotional conditions	10.4%
Paralysis	10.3%
Cancer	9.8%
Autism	9.5%
Missing/malformed limbs	9.2%
Eating disorders	7.5%
Kidney condition or disease	6.9%
Head injury	5.7%
Fetal alcohol syndrome	5.2%
Arthritis or rheumatism	3.4%
Diabetes	2.3%
Cystic fibrosis	1.7%
Spina bifida	1.7%

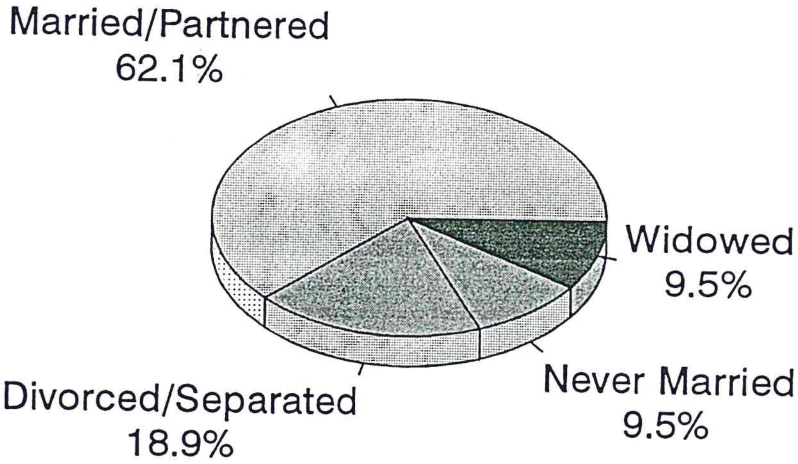
* NOTE: Children could have more than one health problem.

Table 11
Need for Help with Activities of Daily Living

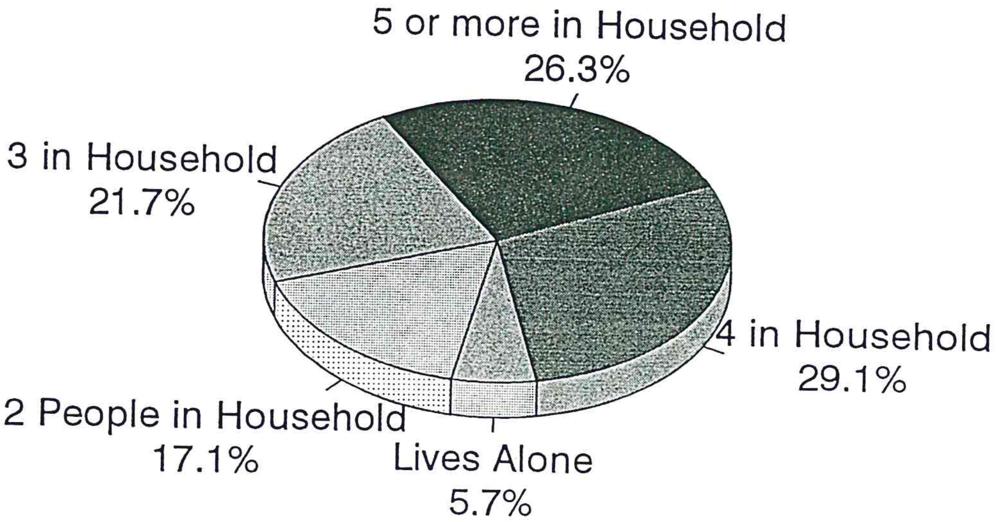
Children aged 6 and over:	% Needing some help	% Completely unable
Eating	25.4%	6.8%
Dressing or undressing	25.6%	12.8%
Grooming (eg. combing hair)	29.1%	15.4%
Getting in and out of bed	4.3%	10.4%
Taking a bath or a shower	27.4%	12.8%
Using the toilet	12.0%	11.1%
Using the telephone	19.7%	19.7%
Children aged 12 and over:		
Getting to places out of walking distance	29.3%	17.2%
Shopping alone	25.9%	25.9%
Preparing meals	29.3%	24.1%
Doing housework (including laundry)	34.5%	19.0%
Taking medicine	34.6%	19.2%
Managing one's money	21.1%	31.6%

Figure 3

Caregivers' Social Characteristics



Marital Status



Size of Household

Mean Household Size = 3.6

each care recipient was 3.1. Less than ten percent (9.8%) of the respondents said they were the sole person providing care, 39.9% said there was one other caregiver involved, 22.5% reported two other caregivers, with the remainder (27.8%) reporting three or more others. These data suggest that the number of individuals involved in caregiving is more extensive than frequently thought. This is not surprising, given the tendency within research to focus on the primary caregiver only. The majority of research has not collected information on others involved in caregiving, and frequently does not include help from formal or paid sources.

Extent of Caregiving

The length of time that caregivers reported being involved in caregiving ranged from less than 1 month to 18 years, and most caregivers reported having provided care for a significant period of time (see Table 4). The average number of years of caregiving activity was 6.6 years and over one-half (56.6%) reported providing care for 5 years or more. Care was generally provided on a daily basis (76.5%). The number of hours of care provided ranged from less than one hour per day to 24 hours per day with the majority of caregivers (57.4%) providing at least 5 hours of care per day.

Gender Differences

Men and women tend to participate differently in caregiving. For example, these data show that women are more likely to be a primary caregiver than men (74.8% compared with 37.5%; $\chi^2 = 19.2$, d.f. = 1; $p < .001$). There is also a significant gender difference in the number of hours given to caregiving, with women putting in more hours: 60.6% of male caregivers put in 3 hours or less per day compared with 29.6% of women; 12.1% of men and 13.9% of women put in 4-6 hours per

Table 7
Caregiver Well-Being

Physical Health - Now	
Excellent/Very good	46.9%
Good	32.6%
Fair/Poor	20.6%
Physical Health - Compared to Last Year	
Better now	28.6%
Same	52.6%
Worse now	18.9%
Emotional Health - Now	
Excellent/Very Good	40.0%
Good	32.0%
Fair/Poor	28.0%
Emotional Health - Compared to Last Year	
Better now	34.3%
Same	48.6%
Worse now	17.1%

as the child receiving the care reported that providing care interfered at least somewhat with their ability to meet the needs of other members of the household. For the most part, this was attributed to the lack of time available due to caregiving.

When asked about the most difficult part of caregiving, caregivers gave a diversity of responses (see Table 8). Over one-half of the first difficulties reported (59.3%) centered around either feelings or concerns which the caregivers themselves were experiencing (such as feeling helpless, dealing with mortality, feeling guilty, familial conflict) or with feelings and concerns that were child centered (such as the suffering of the child, their loss of independence, frustration and so forth). Fewer responses centered on having to deal with formal organizations (6.4%) or on specific problems of the child, such as their deafness, behavioural problems, or mood swings (5.2%). Another 8.1% centered on the child's loss of freedom or privacy. Only 5.8% of the caregivers said there was nothing difficult about caregiving.

Table 8
Difficulties and Rewards of Caregiving

Most difficult part of caregiving.	
Other caregiver centered concerns (feel helpless, deal with mortality, guilt, accept child's illness, family conflict, lack of help)	32.0%
Seeing child suffer (lose independence, feel depressed, frustrated, unable to enjoy things)	27.3%
Dealing with formal organizations	14.5%
Caregiver loss of freedom/privacy	8.1%
Nothing	5.8%
Specific are receiver problems (deafness, behaviour mood swings)	5.2%
Other	14.5%
Most rewarding part of caregiving.	
Impact on child	45.9%
Relationship with child	25.3%
Being able to help	12.9%
Other	12.3%
Nothing	3.5%

Rewards of Caregiving

Caregivers were also asked about the rewards of caregiving, an area rarely investigated in the literature. Few (3.5%) could name nothing that was rewarding. Over one-half (58.8%) referred to their positive impact on the child (45.9%) or to simply being able to help (12.9%). Others (25.3%) referred to the personal relationship with the child (such as the closeness of the relationship, feelings of gratitude and friendship).

Summary

This information on caregivers' needs suggests that, on the one hand, they feel they are coping, and yet on the other hand, they feel stresses and experience difficulties. Interestingly, caregivers were somewhat more likely to report being in poorer emotional than physical health. The tremendous concern of the caregiver for the child comes through when they are asked about the rewards and the difficulties involved. Many talk about their own feelings in coping with what the care recipient is experiencing, the helplessness and so on. The rewards also focus on personal feelings and relationships, especially with the person they are caring for and being able to help that person. These data point to the emotional level and the relationship level as areas of prime importance if we want to relate to caregivers. Caregivers' needs are very human needs. It is in this area that we should be providing assistance, perhaps in the form of support groups or other programs with an emotional component.

Characteristics of Children Receiving Care

Gender and Age

In 1986-87, 5.2% of Canadian children under the age of 15 had a disability of some type. This rate was somewhat higher for boys (5.7%) than for girls (4.7%) and was highest among boys aged 5 to 9 (7.3%) years of age (Health and Welfare Canada, 1990). In the current study, over one-half (58.3%) of the children receiving care were male. They ranged in age from infancy to 18 years of age. Their average age was 8.9 years with two-thirds (66.9%) under 12 years of age (see Figure 5).

Relationships

In terms of the relationship of the child to the caregiver, child care recipients were most likely to be a son (42.5%), or a daughter (27.0%). Overall, close relatives (children or siblings) made up 71.3% of the child care recipients. Other relatives (nieces, nephews, grandchildren, etc.) made up 16.5% and friends and others made up 12.1% (see Table 9).

Table 9
Relationship of Child to Caregiver

Son/stepson	42.5%
Daughter/stepdaughter	27.0%
Other Relative (niece, nephew cousin, grandchild, etc.)	16.5%
Non-Relative	12.1%
Sibling	1.7%

Health

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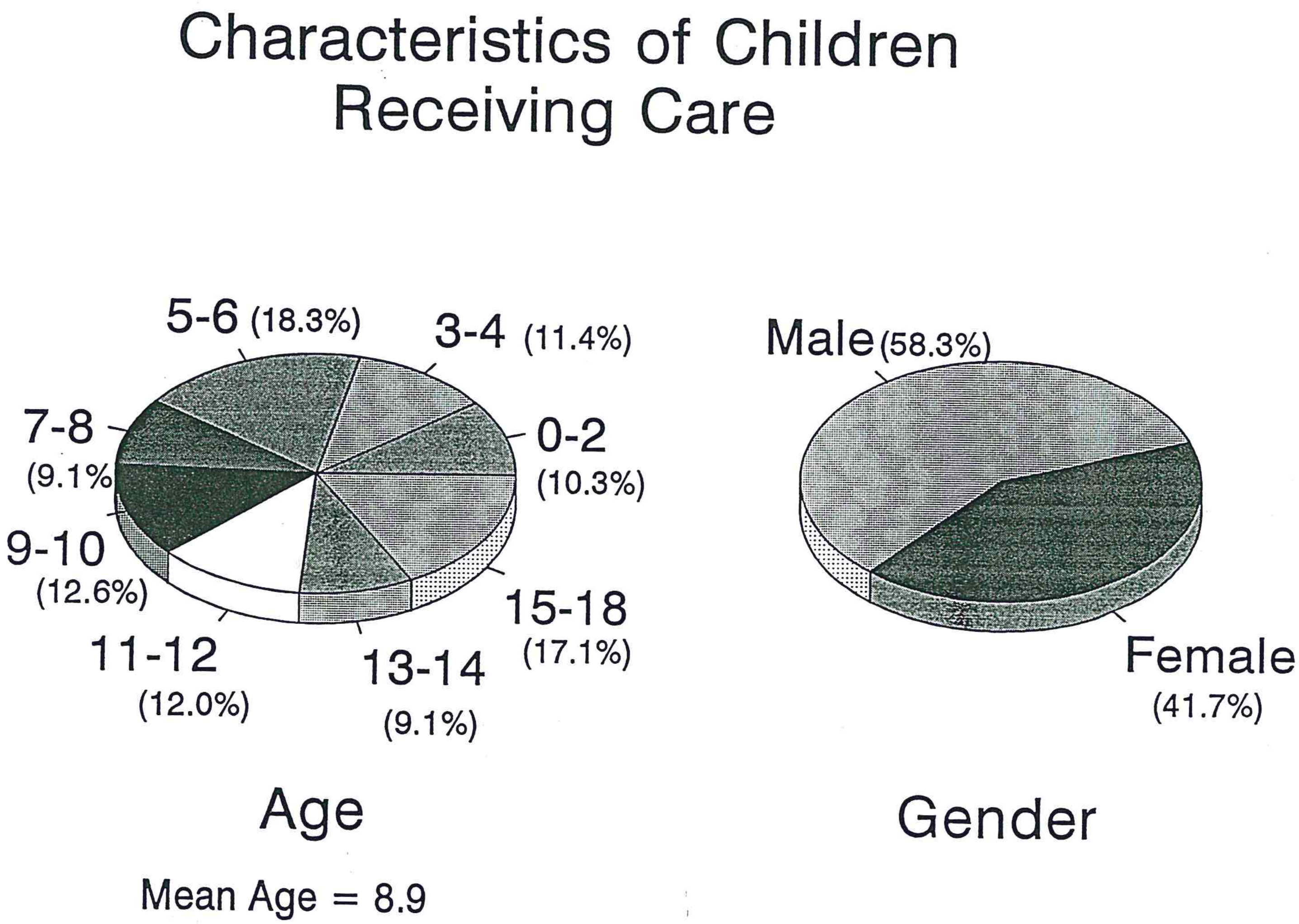
Figure 5


Characteristics of Children
Receiving Care
5-6 (18.3%)
3-4 (11.4%)
0-2 (10.3%)
7-8 (9.1%)
9-10 (12.6%)
11-12 (12.0%)
13-14 (9.1%)
15-18 (17.1%)
Age
Mean Age = 8.9
Male (58.3%)
Female (41.7%)
Gender

children in B.C. with a disability have a hearing problem and about 1 in 7 of those with a disability have a vision problem not correctable by using glasses.

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Doing housework (including laundry)	34.5%	19.0%
Taking medicine	34.6%	19.2%
Managing one's money	21.1%	31.6%

as taking medications, shopping, managing their own money, and going places outside of walking distance. From 17.2% (for getting places out of walking distance) to 31.6% (for managing their own money) were considered completely unable of performing such activities. The level of supervision required by the children aged 12 and over was relatively low: 69.0% of respondents reported that the child, when he or she was not ill, could be left unsupervised for one-half to two hours with no one else at home; 89.5% reported the care recipient could be left unsupervised while someone else was home.

When caregivers were asked whether the child behaved in any ways that caused problems for them in providing care, almost one-third (31.4%) mentioned problems with controlling temper or aggression. Others referred to defiance or stubbornness (15.4%), or other behaviours including hyperactivity, toileting problems, and so forth.

Summary

Children in care are somewhat more likely to be male than female and most are under 12 years of age. They frequently have multiple health problems with the most frequently-cited problems being learning disabilities, developmental delays, and attention deficit disorders. Many require assistance with activities of daily living.

Utilization of Services

Knowledge and Use of Services

Caregivers were asked about their familiarity with various services in the community as well as the services which the child (and/or they themselves, if living in the same household) currently received. The majority of caregivers indicated being

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