



Aging and CP

AGING, WELL-BEING AND CEREBRAL PALSY

Submitted by **The Roeher Institute**

to

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Final Report

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I. Introduction

In the past several years, ensuring that people with a disability experience well-being as they become older adults has emerged as an important concern.¹ The Ontario Federation for Cerebral Palsy frequently fields enquiries about this issue from people with cerebral palsy are encountering as they age. The organization has also sponsored important research and has developed self-help materials on health and aging issues.²

While issues of aging and cerebral palsy have begun to garner interest, the factors that account for the well-being of people with cerebral palsy as they become older are not well known. This research is intended to address that knowledge gap.

II. Objectives and Method

The research sets out to explore how people with cerebral palsy understand the aging process as it affects them personally, the critical determinants of well-being as they grow older, the challenges individuals encounter, and the organizational and systemic policy remedies people with cerebral palsy propose for addressing the issues they face and for building on positive experiences.

Two general research strategies were used: individual interviews and statistical analysis.

Interviews

Individual interviews were conducted with fourteen persons who have cerebral palsy. The purpose of the interviews was to obtain qualitative insight into the aging process as it affects persons with cerebral palsy. OFCP sister organizations in Ontario were approached and asked to assist with the

identification of respondents. Individuals living in rural and urban areas of the province were interviewed and reflect the views of people in a range of living situations (e.g., living alone in own apartment, in Support Service Living Units, with one or more family members, etc.)

The interviews were open-ended. General probes were used to help respondents explore what aging means to them personally, the changes they have undergone as they have grown older, their hopes and apprehensions for the future, the changes they anticipate, and the most difficult challenges they face as they age. Respondents were also asked to identify the most important factors that account for health and well-being as they get older, to offer advice to others with cerebral palsy about the aging process, and to explain how organizations such as OFCP and governments can help individuals who are living with cerebral palsy and aging.

To facilitate research and analysis, The Roeher Institute has developed a social well-being framework.³ It consists of three major elements: self-determination (i.e., participation and mutual recognition in structures and processes for decision-making); equality (i.e., equal status, participation in, and access to the benefits of the social and economic life of the community). The elements are operative at the individual, community and societal levels. The elements in turn are grounded in other conditions widely considered essential in modern democracies: security (personal, family, community, societal), citizenship (i.e., guarantees of civil and political rights) and participation in democratic institutions. The social well-being framework assumes that where the elements are present in the lives of individuals, communities and society at large, a general state of social well-being prevails.

The well-being framework was drawn upon to assist with the design of the interview questionnaires. However, the framework was used in a flexible way throughout the interview process. Interview probes were used to stimulate discussion of issues that may not have come immediately to a respondent's mind. No attempt was made to predetermine what respondents understood to be "health" or "well-being" during the interviews.

Several interview respondents used communication devices. Accordingly, their responses tended to be brief and to the point. As well, several respondents tired during the interview process, which limited the quantity of interview data that could be gathered.

Throughout the report, persons interviewed are referred to as "respondents".

Statistical analysis

Statistics Canada's 1991 Health and Activity Limitation Survey (HALS) was used as the main data source for the statistical analysis. This large data set provides information on a wide range of issues affecting persons with disabilities in Canada. Using data obtained from the screening questions for HALS, a sub-group of about 97,000 persons was constructed whose disabilities arise from the central nervous system. The sample includes persons with cerebral palsy,

multiple sclerosis, epilepsy and other conditions that fall within the International Classification of Diseases Version 9 (ICD9) 340-349 range. Data on the remaining group of 3,435,000 persons identified by HALS has as having disabilities were used for comparative purposes.⁴

Originally it was anticipated that samples could be derived for the province of Ontario only. Unfortunately, the total number of HALS respondents from Ontario who indicated a condition within the ICD9 340-349 range was too small to yield a sufficient level of confidence in the numbers. Instead, the sample pertains to Canada as a whole.

Where the term "the sample" is used in this report, it refers to those having disabilities in the ICD9 340-349 range. The terms "others" and "other persons with disabilities" refer to the comparative group of all persons classified in HALS as having disabilities, excluding those in the ICD9 340-349 group.

Guided by themes that emerged from the interview data, several hundred cross-tabulations were performed and analysed using HALS. To allow for analysis of issues across the adult lifespan, the cross tabulations were stratified according to the following age groupings: 15-34; 35-54; 55-64; 65+.

It is important to point out that the HALS data used for the statistical analysis pertain only to people living in private houses, apartments, co-operatives, rooming and lodging houses, hotels and other buildings of a non-institutional nature and that are privately-owned. Persons living in group homes readily identifiable as such (e.g., in group residences clearly marked with name plaques) and in larger service settings (e.g., mini-institutions, rehabilitation facilities, nursing homes, etc.) are not included in the HALS data used for the statistical analysis. However, the statistics represent the situation for most persons with disabilities because relatively few live in non-private/ institutional situations (only 6.3 per cent of all adults with disabilities in Canada).

Demographic data on interview respondents were also gathered (e.g., age, gender, income). This information has been integrated across the various sections of the report, including the footnotes.

Advisory group

A small advisory group consisting of administrators, consumers and other persons knowledgeable about Cerebral Palsy was created to provide input to Roeher Institute researchers. Advisory group members provided input to the design of the research and critical feedback on an interim report.

Structure of the report

To the extent possible, the results of the interviews and statistical analysis have been integrated together rather than being presented as "stand alone" research products. However, general demographic information on the HALS statistical sample and on the people interviewed is provided in a separate section as a general orientation to the reader. Much of the interview data clustered around the factors that interview respondents said need to be in place to ensure their

personal well-being and health. Accordingly, these issues were made a major focus of the report.⁵ Implications for service providers are presented in this context throughout the body of the report. Implications for organizations such as the OFCP and for government are presented in a separate section on policy options.

III. General Demographics of the HALS and Interview Samples

Age

As a group, the group sampled is younger than other persons with disabilities. Among persons aged 15 and older, the average age in the statistical sample is 50; among other persons with disabilities the average age is 58. Some 12.1 per cent of the group sampled are between 15 and 24 years of age. This is true of only 7.3 per cent of all other persons with disabilities.

Similarly, among those interviewed, the average age was 44. Some 14.3 per cent were aged 25 or younger.

Gender

Females make up a larger share of the sample group than males (57.9 as compared with 42.1 per cent). However, as people in this group aged beyond 65, the over-representation of females decreases; only 49.4 per cent of the older group are females. In contrast, among other persons with disabilities, females make up a larger share than males of the 65 and older group (59 per cent) but a roughly even share among people younger than 65.

Among the people interviewed for the research, 64.3 per cent were females.

Family characteristics

The younger age of the sample may help account for why a much larger share are never-married children living with one or more parents (14.2 per cent as compared with 7.6 per cent among all other persons with disabilities). Roughly equal proportions of the statistical sample and other persons with disabilities are wives or female common law partners (25.9 and 24.2 per cent respectively). A much smaller share of the sample (22.9 per cent) are husbands or male common law partners than among other persons with disabilities (30 per cent).

Among those interviewed, 14.3 per cent were living with biological or extended family members.

Overall, people in the statistical sample are more likely than other people with disabilities never to have married (34.3 as compared with 20.4 per cent), a pattern that may simply be a function of the younger average age of the sample.⁶ As people in the sample age, however, they are more likely than other persons with disabilities to enter into legal marriage. Fewer than one per cent of people 65 and older in the sample have never married, compared with 10.1 per cent among other persons with disabilities.

Ever-married persons in the sample are not significantly more prone than other persons with disabilities to have their marriages end in legal separation or divorce or to lose their spouse through death.⁷ This finding is most evident for persons 65 and older. Among younger people who have ever married, those in the sample are in general less likely than others with disabilities to have their marriages end in separation, divorce or death of spouse.

Where living with family members, people in the sample are living with three people on average. Others with disabilities are living with two people on average. People in the statistical sample are less likely than others with disabilities (16.8 compared with 21.8 per cent) to be "unattached" persons, that is, persons living alone or living with others but not with family members, such as in a rooming house.⁸

Women in the sample are less likely than other women with disabilities to have had children (62.9 compared with 75.6 per cent). However, women 65 and older in the sample are much more likely than other women this age with disabilities to have had three or more children (64.9 compared with 37.8 per cent). More than half of all women 65 and older in the sample (55.9 per cent) have had five or more children.

Age of disability onset

Establishing the exact age at which disability began is problematic using HALS. However, one of the HALS questions asks whether survey respondents had their disability before completing their formal schooling. Among those in the sample, 39.3 per cent had their disabilities before that point in life, compared with 25.2 per cent among all other people with disabilities.

Education and literacy

The education and literacy profiles of persons in the sample and others with disabilities differ significantly. Those in the sample are more likely over all than others with disabilities to have a high school diploma or a higher level of education (49.3 compared with 36.7 per cent).⁹ However, young adults (aged 15 to 34) in the sample are less likely than others this age with disabilities to have achieved high school graduation or more education (49 compared with 60.9 per cent). In contrast, people 35 and older in the sample are more likely to have completed high school or a higher level of education than others with disabilities.

In the sample, a striking 40.9 per cent aged between 15 and 34 say their reading and writing skills are below average or are inadequate for daily living. This is true for only 20 per cent of others with disabilities this age.¹⁰

Among those in the statistical sample who indicate having low literacy skills, 52.8 per cent also say they have been told by a teacher or health professional that they have a learning disability, such as dyslexia, a perceptual handicap, attention problems or hyperactivity. This is true for only 18.9 per cent of other persons with disabilities who have low literacy skills.

Other demographic details are provided throughout the body of this report.

IV. What Is Aging?

Interview respondents were asked several general questions to probe their perception of what it means to age with cerebral palsy. The views expressed were diverse. Some respondents had not given the issue much thought; others did not want to think about the issue. "I try not to think about it much", said one. "Why get myself uptight about what the future might or might not have in store for me", a view echoed by several other respondents. A few others indicated that aging is simply "a state of mind."

However, clearer ideas on what it means to grow older with cerebral palsy did emerge from the interview data. These revolve around coping with various losses and physical complications, making life transitions, and finding satisfactions in life.

Loss

Many respondents indicated that getting older means having to come to terms with various losses. Some respondents focused on lost or decreased ability to do activities of daily living; others feared losing their present abilities at some point in the future. "I can't do all the day-to-day things by myself", said one respondent. One said, "Walking is getting worse" and another that, "My hand movements are no good now". Another said, "I feel that I will become even slower than I am now. This makes me very frustrated and angry." One respondent is now concerned about having to stay in bed most of the time, whereas she would prefer to be up and active like previously in her life. Another said the hardest thing about aging was that "My mind wants to do things quick, but my body won't follow the instructions". Several respondents indicated that reading is more difficult now that they are older. Several expressed fear that their mental faculties may begin to weaken; "I'd rather be dead", said one.

On several points the statistical analysis confirms these impressions of aging given by interview respondents. Persons in the sample are much more likely than others to have disabilities that Statistics Canada classifies as "severe" (37.3 per cent as compared with 17.5 per cent).¹¹ However, the severity of disability does not increase steadily with age. Surprisingly, persons aged 65 and older in the sample are less likely than those aged 55 to 64 to be severely limited in their activities.¹² The following table shows the increases in the presence of severe levels of disability for the sample and for other persons with disabilities as they age (Table 1).

Table 1. Proportion of two groups with severe levels of disability, by age.

AGE GROUP	SAMPLE	OTHERS WITH DISABILITIES

15-34	26.0	7.1
35-54	39.4	14.0
55-64	51.6	19.0
65 +	44.1	25.0
TOTAL	37.3	17.5

The statistical analysis also found that people in the sample are more likely than others to have a variety of disabilities. Table 2 shows that some disabilities become more prevalent as individuals age (hearing, seeing, mobility and agility), whereas the prevalence of other disabilities (speaking and "other"¹³) decreases with age for the sample. This general pattern is true for other persons with disabilities as well. However the prevalence "spread" across the lifespan is not as great for persons outside the sample.

For example, they may become increasingly prone to hearing loss, but to a lesser extent than people in the sample.¹⁴

Table 2. Types of disabilities for the sample and others with disabilities

SAMPLE

Age	Hearing	Seeing	Speaking	Mobility	Agility	Other
15-34	18.8	14.1	43.7	60.0	58.8	70.5
35-54	25.6	19.4	24.4	74.6	65.9	63.7
55-64	27.6	15.7	17.3	82.5	71.0	49.4
65 +	56.9	43.7	7.5	56.1	73.7	26.4
TOTAL	31.5	23.6	25.8	65.8	66.0	55.1
		Others	With	Disabilities		
15-34	18.8	6.5	10.7	35.6	35.1	41.7
35-54	24.9	9.5	6.1	52.5	52.3	29.6

55-64	31.0	11.1	4.6	67.9	61.1	23.3
65 +	40.8	23.7	5.1	72.1	60.5	25.7
TOTAL	30.4	14.2	6.3	59.0	53.6	29.3

Statistical data show that reliance on others increases with age as well, particularly for people in the sample. Over all, they are more likely than others to need help from others with everyday activities, such as shopping, meal preparation, chores, personal finances, movement about home, and personal care¹⁵ (74 compared with 51.9 per cent). This need becomes more common as they age. At age 65 and older, 83.7 per cent of those sampled need help from others with everyday activities, compared with 65.6 per cent of those aged 15 to 34. Among others with disabilities aged 65 and older, only 66.9 per cent need help from others.

Loss of function and independence, however, are not the only losses people interviewed associated with aging. Some, for instance, cited the loss of employment as a difficult fact of life they had to deal with as they got older.¹⁶ A young adult who had his heart set on going to college said not being able to go was a frustrating loss to cope with. Another said he is less tolerant now that he is older. Another indicated he now has less of the spare time he needs to do the things he wants. Two female respondents spoke about their strong desire to have children, an option closed to one because of menopause and that may be closing to the other because of her circumstances. Other interview respondents spoke about their increasing loneliness, their loss of friends and their fear of losing friends and family.¹⁷ Several talked about the emptiness that comes with the death of family members and friends, some respondents looking to their own death with greater anxiety than others.

Physical complications

Aside from losses, interview respondents identified a range of new physical complications they have to deal with as they get older. One, for instance, talked about bowel problems that have become an increasing nuisance and which present risks to his physical health. Several others spoke about increasing stiffness in their muscles, joints and limbs, expressing concern that the problem could get worse. One spoke about late-onset digestive problems that are affecting her diet and reaction to foods. Others talked about arthritic and other pains.

Statistical data shed some light on the degree to which people in the sample have general trouble with pain or discomfort. As a group, persons in the sample are less likely than others with disabilities to have this problem (41.6 as compared with 53.1 per cent). Of particular interest, persons aged 65 and older in the sample are much less likely than others this age with disabilities to experience general pain or discomfort (18.7 compared with 58.8 per cent, Table 3). Among those who are experiencing pain, however, those in the sample are

increasingly more prone to "moderate" levels of pain as they age. For other persons with disabilities who experience pain or discomfort, the pattern of pain intensity is more constant across the lifespan (Table 4).

Table 3. Proportion having general trouble with pain or discomfort

AGE GROUP	SAMPLE	OTHERS WITH DISABILITIES
15-34	33.4	43.8
35-54	62.4	57.4
55-64	62.5	61.7
65 +	18.7	58.8
TOTAL	41.6	53.1

Table 4. Among those having general trouble with pain or discomfort, proportion experiencing a moderate levels of pain/ discomfort, by age group

AGE GROUP	SAMPLE	OTHERS WITH DISABILITIES
15-34	30.9	55.5
35-54	49.8	48.0
55-64	57.5	49.5
65 +	79.9	50.0
TOTAL	49.6	50.1

While some respondents said their health was deteriorating as they get older, or that they worry about it deteriorating in the future, most said they had no major health concerns. In part this may be due to the good care they seem to be taking of their physical health, an issue that is examined in Section V of this report.

Life transitions

Interview respondents identified key life transitions they made which impressed on them the fact they were getting older. For several, moving from the family home was a major step. In the words of one woman, "Moving away from my family after high school graduation was a big change and learning experience for me. It was a good decision. I made a lot of mistakes but learned from them".

This individual wanted her independence and to be treated like other people, but was living in a region of the province where there were no support services that would have enabled these things to happen. Another had to leave home because her parents were no longer able to care for her, a move which made her feel her age. Another respondent indicated that leaving home meant not having to answer to adults and having to take responsibility for his own decisions, good or bad. He enjoys the independence this change signalled.

Indeed, one respondent spoke about her strong and growing desire for independence over the years. For her, this is the single most important indicator she associates with aging.

Several other respondents spoke with relief about leaving institutions for adult life in the community. Others, however, look with varying degrees of apprehension at their possible institutionalization late in life.¹⁸

For several respondents, the transition from low technology support device (e.g., a walking cane) to a higher technology device (e.g., a walker or wheelchair) was tangible evidence they were aging. One individual expressed concern about becoming too dependent as he gets older on technology, medications and dietary supplements that assist with eliminating bodily wastes.

One female respondent identified menopause and other changes in her sexuality as the main age-related transition she is having to cope with. For her, this is a difficult issue, not only because it means she can no longer have children, but because neither her parents nor others had prepared her earlier in life to address the physical and emotional changes she is experiencing.

Finding satisfactions

Several respondents spoke about various pleasures they associate with getting older. In this respect, their experiences probably mirror those of most of the general population. For one this includes having more time to do the things she wants. She counsels young people with cerebral palsy to build time into their lives to enjoy things, something she had not done when she was younger. Another said he most enjoys "Watching kids -- their eyes lighting up at Christmas time. To be around children and to watch them grow. To see them go through the things I also went through and to see them face new challenges." Another takes pleasure in frequent outings with her boyfriend. Another said, "I knew I was getting older -- and better -- when my reading level improved". Several spoke with satisfaction about their knowledge and acquired wisdom gained over the years. One individual identified his house and his greater financial security as some of the better aspects of getting older.

Several interview respondents pointed to the improved accessibility of communities, the increase in activities available to persons with disabilities and better opportunities as some of the key benefits they are able to enjoy now that they are older. These respondents were comparing their present situation to when they were younger.

V. Physical Determinants of Well-Being As People Age

When asked about the most important thing that needs to happen to maintain well-being for them personally as they get older, most interview respondents pointed to the importance of physical factors that affect bodily health. The advice of one respondent to young people was, "Learn to care for your body -- work at it -- don't just leave it to nature."

Good nutrition

In particular, several respondents cited the importance of good nutrition. As one respondent says simply, "Eat well." Another indicated good nutritional intake is an ongoing concern because his personal eating preferences are not always consistent with a well-balanced diet.

HALS 1991 is silent on nutritional intake, so it is not possible to use those data to see how people in the statistical sample rate their eating habits. However, using HALS 1986 it was found that, as people get older, people with disabilities in the ICD9 340-349 range are increasingly likely to rate their eating habits as "poor" or only "fair" (17.3 per cent among persons aged 15 to 34; 33.6 per cent among persons aged 65 and older).¹⁹

Physical activity

Several respondents indicated that physical activity is particularly important for their personal well-being. In the words of one, "Keep moving and keep active... keep up your mobility. Exercise as much as you can to keep muscles nimble". The advice of one respondent to others is to "Keep pushing yourself to move. Get up. Keep physically active". Another wondered whether she would presently be able to do more in life if she had kept physically active when younger, but indicated that staff at the nursing home where she lived had no time to help her keep doing this.

Specific forms of physical activity that respondents identified as important for well-being and health include swimming, stretching, and exercise programs. One respondent indicated that even activities such as crafts can be important "to get your hands going".

The statistical analysis found that persons with disabilities are in general less inclined to be physically active in their leisure activities (e.g., gardening, swimming) as they get older. This is true for persons in the sample as well. However, younger people in the sample are 2.3 times more likely to be physically active²⁰ than those 65 and older. This is a more extreme decline in physical activity over the adult lifespan than among others with disabilities, where younger people are only one and one-half times more likely to be active than seniors.

Over all, a lower share of the sample indicate they participate in physically active leisure activities than is the case among other persons with disabilities (55.6 compared with 64.5 per cent). A fairly high share of persons in the sample who are between 35 and 64 years of age would like to be more physically active

(62.1 percent of those aged 35 to 54; 60.4 per cent of those aged 55 to 64). In contrast, seniors in the sample seem satisfied with their physical activity level (only 17.8 percent would like to be more active, compared with 41.2 per cent of other people with disabilities this age).

There is also a dramatic decline across the adult lifespan in activities that can maintain fine motor skills, such as arts, crafts and other hobbies. Among those in the sample, 69.1 per cent aged 15 to 34 participate in such activities occasionally or regularly. Among those aged 65 and older, only 10 per cent ever do such activities.

The role of physical activity in her life led one respondent to stress the importance of there being enough physical activity programs for people with cerebral palsy who are getting older. Another who is frustrated with recreation programs that say they are accessible but lack the necessary staff, remarked, "If you are going to set up a service, do it properly."

Lack of programming and inaccessible programs, while significant issues, are not the main reasons given in the statistical analysis for the decline in physical activities with age. The two main reasons among those who would like to be more active are physical inability to do more (84.3 per cent) and the high cost of participation (39.7 per cent). Next in order are lack of nearby facilities or programs awareness about suitable physical activity options (17.5 per cent), lack of attendant service and inadequate transportation (both at 16.9 per cent), inaccessible facilities, equipment or programs (13.9 per cent), and finally, lack of support by family or friends (9.7 per cent).

All persons 65 and older in the sample indicated that physical inability to do more is the main reason why they are not more physically active, followed in distant second place by the high costs of participation (12.6 per cent). This raises the question whether older persons might be more physically active had the conditions for participation been more available to them earlier in the lifespan.

Caution in the use of medications

One respondent cautioned about the risks presented by medications to physical health. He counselled "Don't over-medicate yourself", even if using medications for health-related aims. This caution is probably well founded, given the widespread use of medications by those in the statistical sample. They are more likely than others with disabilities to be using medications on a regular basis (73.6 as compared with 61.5 per cent). In the sample group, 67.9 per cent take one or more prescription drugs daily.

Medication use increases with age for both groups. Almost all persons aged 65 and older in the sample (96.7 per cent) use medications regularly. The vast majority this age in the sample (92.8 per cent) take at least one prescription drug daily.

As they age, persons in the sample are more likely to self-administer their own

medications. Among those aged 65 and older, 96.2 per cent organize their own medications, compared with only 54.2 per cent of those sampled between 15 and 34 years of age. Among other persons with disabilities, the self-administration of medications remains fairly constant regardless of age (ranging between 81.2 and 84.4 per cent).

These findings point to the need for persons with cerebral palsy -- and pharmacists -- to safeguard against chemical dependency and to be alert to the potential for adverse interactions between medications.

Avoiding health-risk behaviours

A respondent reflecting upon the changes in his own behaviours as he aged said, "I smoke more, don't drink as much." Statistically, this individual seems to be fairly typical. People in the sample are more likely than others with disabilities to smoke regularly (32.3 compared with 24.9 per cent). Adults aged 35 to 54 and seniors in the sample are most likely to smoke regularly (43.9 and 30 per cent respectively).

However, people in the sample are less likely than others with disabilities to drink alcohol (48.2 compared with 61.8 per cent ever do so). This may be due in part to the risks of adverse reactions between medications and alcohol. Among people 55 and older, a large proportion in both the sample and among other persons with disabilities never consume alcohol. Unlike others with disabilities, however, a high share of younger and middle-aged adults in the sample avoid alcohol altogether.

Other physical health considerations

Other considerations to maintain physical health revolve around the elimination of bodily wastes. For instance, one individual who has significantly limited bodily and limb movement said it is important to "...flush out my system to keep going. If that goes I could end up wearing pads and getting skin break-down". Turn et al (1995) provide more detail on other physical health issues persons with cerebral palsy are increasingly likely to face as they get older.²¹

Access to health care services

Because maintaining physical health is important, some respondents felt access to adequate health services is a critical determinant of their well-being. For instance, one respondent pointed to the need for "Enough doctors to help with ailments." Another would like greater availability of outpatient services for physiotherapy.

Like other people with disabilities, very few people in the sample needing health-related services have difficulty obtaining them.²² Only 6.8 per cent say this is a problem. Difficulty obtaining services decreases with age. No people aged 65 and older in the sample indicate they have had difficulty getting the services they need (only 4.9 per cent among other seniors with disabilities). Given current and proposed reforms to Canada's health care system, time will become a bigger issue for persons with cerebral palsy.

If the availability of health-related services is an important consideration, some respondents indicated that the quality and responsiveness of service provided is also critical. As one pointed out, "Doctors need to be prepared to take time to listen," a view shared by several others. One respondent said that doctors need to "better recognize the condition instead of asking the patient whether or not they think they have CP." Her condition was not diagnosed until she was in her thirties. Aside from needing clinical knowledge, this respondent felt doctors also require more general information on the needs of persons with cerebral palsy. Then again, other respondents pointed out that cerebral palsy may have nothing to do with the problem an individual wants treated, yet may find health care professionals dwell on cerebral palsy to the exclusion of other, obvious, health concerns (e.g., a broken toe).

Table 5, which was developed using HALS 1986,²³ shows that persons in the sample group are generally more likely than others to have seen one or more health-related professionals in the past three months. The table underscores the need for sensitive, knowledgeable health care professionals in the past three months. The table underscores the need for sensitive, knowledgeable health care professionals

Table 5. Percentage of those sampled and others with disabilities who have visited a health-related professional in the past three months.

PROFESSIONAL CONSULTED	SAMPLE	OTHERS WITH DISABILITIES
Physician/medical doctor	71.0	68.2
Chiropractor	8.4	6.7
Nurse	14.5	6.1
Therapist (physio/ occupational/ speech)	10.0	5.5
Other health professional	19.7	25.3

VI. Subjective Determinants of Well-Being as People Age

Attitudes and outlook

While the body has its needs that have to be addressed, most respondents also spoke of the importance of the attitudinal and mental determinants of personal well-being. Said one respondent, "My physical health is important. But more importantly, my mental health is what I want to maintain. The mind is a very powerful tool if used wisely and properly." This respondent said, "I am full of life and active... I work at having a positive attitude and have done so for the past seven years."

Indeed, several respondents indicated that a positive attitude is key to their personal well-being. One respondent said it is important to have "a good outlook on life. Some people complain of aches and pains, but would rather look on the brighter side". Another said, "I have to keep a positive attitude, and remind myself to do just that". The advice of another is, "Don't let your mind go. Keep your spirit alive." Presenting the other side of the coin, another respondent indicated that a positive outlook can be difficult to maintain. Clearly worn down by life's experiences, he said, "Things used to be optimistic for me. I have become weary and cynical. It has been a gradual progression to feeling this way".

Most people in the sample (78.7 per cent) indicate they feel either "very happy" or "pretty happy" with life in general (80.1 per cent among others with disabilities). However, these feelings of well-being are not so widespread among middle-age adults. For example, 34.2 per cent of those between 35 and 54 years of age in the sample feel "not too happy", as do 25.8 per cent of those aged 55 to 64. Seniors in the sample are least likely of all to indicate they are unhappy (only 8.4 per cent).²⁴ Age-related changes in feelings of well-being are not as noticeable among others with disabilities. For these persons, retirement-age persons are only slightly more likely than young adults aged 15 to 34 to often feel either very happy or pretty happy (88.1 per cent as compared with 85 per cent).

Middle adulthood seems to be a particularly difficult time for persons in the sample. Not only are they less likely to say they often feel happy, those aged 35 to 54 are more likely than at any other point in life to say they have been told by a professional (i.e., health care professional, social worker, counsellor) they have a major mental health problem, such as depression, manic episodes, schizophrenia, a nervous breakdown or other serious emotional problem (45.2 per cent; 26 per cent overall). In contrast, only 4.6 per cent of people sampled in the 65 and older age group have been told this by a professional. Others with disabilities are also more likely during the years from 35 to 54 to have been identified as having a serious mental health problem (28.3 per cent). However, the prevalence of this problem does not vary so widely according to age (21.6 per cent over all).

Several respondents pointed to personal qualities such as confidence, the spirit of independence and the will to achieve as inner determinants of well-being and health. Said one respondent, "Do what you feel is in your heart. You know your body best and what you need". Another echoing the same theme said, "If you can do it yourself, then go for it". Another advised young people "Take advantage of every possible opportunity. You have so much more than we did. Go for it!"

Statistically, persons in the sample are more likely later in life than in middle adulthood to feel pleased about accomplishing something. Nearly 94 per cent older than 65 said they often or sometimes feel this way, compared with 87.7 per cent across the sample over all. Those least likely to feel pleased about accomplishing something are aged 55 to 64, with only 77.1 per cent feeling this

way. In contrast, others with disabilities are less likely to feel satisfied about their accomplishments beyond age 65 than at any other point in life (84.7 per cent, compared with 89.3 per cent over all).

Speaking about what service providers can do to build self-confidence, a sense of accomplishment and independence in people who are getting older, one respondent said they "should help people... do things that they have great difficulty doing, but should let them do their other work completely independently". Several other respondents emphasized this point as well. One respondent said she does not like having other people do things for her because they end up doing it the way they want. "And besides," she said, "they just want to get their way."

Openness to learning

Several respondents indicated that a will to learn and experience new things is essential for maintaining personal well being. Advised one person who was interviewed, "Continue to learn new things." Another said, "I hope to go back to school and continue learning. I want to study English." Another advises young people, "Continue your education as long as possible" a point reiterated by another respondent who believes young people should focus on getting an education that can help them get a long-lasting job. The latter respondent regretted high school counsellors who were unable to provide her much help in making wise course selections earlier in life.

For reasons that are not clear, persons in the sample aged 65 and older are much less likely than younger people to indicate they are particularly excited or interested in something, plunging to only 1.4 per cent from 17.1 per cent over all and from a high of 24.5 per cent among people aged 15 to 34. Other people with disabilities, too, tend to become less interested in things as they age. However, disinterested or excited compared with 30.3 per cent among those aged 15 to 34.

If feelings of intense interest and excitement subside with age, persons in the sample group are much less likely than others to say they often feel bored (7.3 per cent compared with 17.9 per cent across the entire sample). Seniors in the sample are also less likely than other people with disabilities 65 and older to often feel bored (11.1. per cent).

Moreover, people 35 and older in the sample are much more likely than others with disabilities to have returned to school at some point in life for re-training (38.7 compared with 25.4 per cent). Those in the sample most likely to return to school are aged 35 to 54 (40.3 per cent).²⁵ The motive to return to school may stem in part from inadequate literacy skills acquired early in life and the disadvantages low literacy create in the labour market (See Section III).

Acceptance without fatalism

Interview respondents pointed to the balance people with cerebral palsy need to achieve between accepting things as they are on the one hand, and falling into a fatalistic attitude on the other. For instance, "Don't give up on people. Don't

give up on yourself", advised one respondent, and "Don't give up. Keep trying new things every day. Do what you do best", said another. However, another respondent finds it is important for him "to be relatively content." He said, "I don't want to be one of those people who complain all the time in their old age". Another said, "Don't take things too seriously, which I do a lot." Similarly, when asked to give advice to young people with cerebral palsy about aging, one respondent felt that they "should not physically struggle too much as this can only lead to much frustration". Another said, "Tell people their disability is not going to change that much unless they go through intensive therapy to improve agility and mobility. Even then the improvements are rare and can usually only be seen months and months later, sometimes never". However, while urging caution about trying to change the basic fact of disability, this respondent wished she would have pressed more vigorously for physiotherapy when younger.

Statistical data suggest people in the sample may have more difficulty as they age "taking things in stride". When asked how often they have felt "things were going your way", 35.3 per cent of sampled persons 65 and older indicated "never", compared with only 28.8 per cent of young adults aged 15 to 34. Among other people with disabilities, the proportion of people who feel things never go their way holds relatively constant in the adult years, ranging between only 18.3 and 20.6 per cent. One individual who was interviewed spoke poignantly about addressing the difficulties she has faced. "I can only hope that my life will get better than it is now. I have had so many bad things happen to me that I think something good just has to come out of all this."

VII. Social and Economic Determinants of Well-Being as People Age

Not all the determinants of well-being and health can be summarized in the terse advice of one respondent to young people, "Be happy. Do exercise." Interview respondents also identified social and economic factors as essential.

Respect from others

Maintaining an enthusiastic attitude towards life is not always easy and can hinge on interactions with others. One respondent said that, for her well-being and health, "I need to be treated with respect." Another said young people with cerebral palsy need to "get people to believe in your dreams." One expressed frustration that her parents seemed unable to grasp that her "aspirations are real ones". Another is concerned about how people perceive him now, but worries more about how people will perceive him in the future.

One person said it was important for service providers to "Try to have respect" and to "Listen to the person". Several others urged that service providers be more patient. Another feels it is important for service providers to try to bridge social distances: "Talk with the person, and don't think we are retarded", a point emphasized by a number of people interviewed. A young adult wished service providers would "treat us like people, not like babies" and "Take time to talk to us." She also feels it important that service providers understand "we need a

life", meaning that activities such as physiotherapy and school are not necessarily the most important things to people with cerebral palsy.

Relationships

For some, a key determinant of personal well-being is having relationships with others. One cited the importance of "friends who visit", and several others expressed the desire to have more frequent visits with family and friends. Another echoing this theme said, "I hope to have more [friendships]. I seem to be by myself a lot. When people come into my life, it's a joy. I seem to have a hard time keeping friendships -- I don't know why." Another fleshed out the general point by saying that it is important for her to be involved with "People who are not just helping for the money, but who genuinely care." Another commented somewhat bitterly, "No matter how nice they [service providers] are or how well they get along with me, they all do it for the money. All of them." One respondent set as a key life goal creating a strong personal network of friends around herself.

Feelings of loneliness are more common among middle-age adults than among seniors in the sample. For example, 20.9 per cent of those aged 35 to 54 often feel lonely, compared with only 8.1 per cent among people sampled 65 and older. In fact, as people in the sample age, they are increasingly more likely to say they never feel very lonely or remote from other people. This is somewhat surprising in that 38.4 per cent of people in the sample aged 65 and older never take part in social activities or visit family or friends in their spare time (compared with only 16.9 per cent in the sample as a whole).²⁶ Moreover, seniors in the sample have less social contact with others by telephone than at any other point in their life.²⁷ In contrast, one young adult who was interviewed said "My phone is my life line." The lower than expected sense of loneliness among seniors in the sample also runs contrary to much of the academic literature on aging, which associates loneliness and isolation with poverty among those aged 65 and older.

Increasing importance of informal support

The declining sense of loneliness among people in the sample as they age may be partly a result of their support arrangements. While people in the sample are less likely to seek out others by visiting and using the telephone, they become more likely than others as they age to have people in their lives who support them on a non-paid basis. For example, people in the sample are overall much more likely than others with disabilities to be receiving some form of human support with everyday activities (70.1 per cent compared with 46.8 per cent). While the need for human support increases with age for both groups, people in the sample are much more reliant than others on the informal help provided by family members, friends and neighbours. Some 51.1 per cent of the sample get informal support exclusively, compared with only 31.1 per cent among others with disabilities (i.e., they get no help from voluntary or for-profit service agencies). Most seniors in the sample (69.6 per cent) are supported informally by family, friends and neighbours only, compared with only 33 per cent of other seniors with disabilities.

Losing or not being able to secure supportive relationships with family and friends in old age was presented by several respondents as one of their central concerns about aging. Several respondents spoke about their intention to share an apartment with a friend to address this challenge.

The heavy reliance by persons in the statistical sample on informal supports points to the need for program responses to ensure those providing informal support are themselves getting the help they need. The finding also raises questions about whether those in the statistical sample have less entitlement than others to community service programs.

Access to support services

Several interview respondents underscored the importance of support services now and as they get older. Said one, "There are not enough programs for people with disabilities who are my age". This individual is afraid of ending up in a retirement home and losing her independence as a result. In contrast, another respondent is looing to a retirement home, not only to help fight off loneliness, but to provide the help she needs with everyday activities. Another individual who was interviewed is frustrated at the lack of housing programs that also provide disability-related support services, the long waiting lists for the few programs that are available, and how these factors block his independence and life choices. Another respondent hopes he will have access to inclusive rather than segregated seniors' services when he is a senior citizen. Another respondent is concerned about what would happen if service workers went on strike. He indicated that he would probably have to go to a hospital or nursing home. Many of those interviewed (42.9 per cent) were concerned about losing their support services.

Statistically, gaining access to community services is increasingly an issue for people in the sample as they age. As discussed, people in the sample are more likely than others to need help from others with everyday activities, and become more in need of such help as they get older. However, only 16.8 per cent of those 65 and older in the sample who need help get any from voluntary or for-profit service providers. In contrast, 43.9 per cent of others this age who need help get some from organized services.²⁸ These findings underscore the importance of the informal support provided by family, friends and neighbours for persons in the sample.

Aids and devices

All of the persons interviewed for the research used an aid or device because of their disability. Many who were interviewed (64.3 per cent) indicated that they lack the aids/devices they need. For example, one person who was interviewed has no option but to use a wheelchair that does not fit her properly. The lack of a proper wheelchair hampers her independence and ability to participate in the community. Another individual needs a new wheelchair and various medical supplies but cannot afford them. Lack of access to needed aids and devices is due in large measure to inadequate incomes for basic needs and disability-related supports (see below).

People in the sample are much more likely than others to need aids and devices to help with mobility, seeing, hearing and speaking (89.1 per cent 71.7 per cent). As with others who have disabilities, this need increases with age; virtually all people in the sample 65 and older need such supports.

On a positive note, most people with disabilities who need aids and devices indicate they have what they require. However, the likelihood increases with age that such needs will go un-met. This is particularly true for people in the sample; 21.1 per cent aged 65 and older need more aids and devices than what are available to them, compared with only 11.6 per cent who are aged 15 to 34.

Money

Among those interviewed for the research, 69.2 per cent had total incomes from all sources of less than \$15,000.²⁹ Not surprisingly, several respondents indicated that having enough money for basic necessities (e.g. housing, food and utilities) has an important bearing on their personal well-being. Others spoke about the need for financial assistance for disability-related costs (e.g., equipment purchases and repairs).

Some respondents indicated that financial worries are easing somewhat as they get older. Others expressed no particular fears about the likelihood of having enough income as they get older. Some people who were interviewed, however, indicated this is a persisting problem. For example, several respondents have difficulty making ends meet. One who was interviewed cannot afford transportation or catheter supplies, and cannot afford his share of the cost of equipment purchases that are partially covered under Ontario's Assistive Devices Program. This person, like another respondent, indicated that funds for equipment are easier for children than adults to obtain, thanks to targeted contributions by voluntary organizations such as Easter Seals. Another respondent said she had to approach a bank for a loan to repair her wheelchair because her Family Benefits case worker had refused the money she needed. Only when the case worker found out about bank approval for the loan was the needed FBA funding released.

Inadequate income is a significant problem for persons in the statistical sample. They are more likely than others with disabilities to have incomes that place them below Statistics Canada's low income cut-off -- the unofficial "poverty line" (26 compared with 21.8 per cent). Those in the sample receiving disability-related income from a public or private plan are much more likely than others to be living below the low income cut-off (43 per cent compared with 17 per cent for those not receiving such income). This is hardly surprising: poverty is often a necessary condition for access to income support.

People aged 35 to 54 are the most likely of all in the sample to be living below the poverty line (37.9 per cent, and 55.8 per cent if they are receiving disability-related income). Of some interest is that seniors in the sample are least likely of all to be living below the poverty line (6.4 per cent). They are even less likely to be living in poverty if receiving disability-related income from a public or private plan. The latter finding may mean that seniors are more likely than younger

persons to be gaining access to income support on the basis of factors aside from poverty (e.g., through entitlement programs such as Old Age Security rather than through means-tested programs such as welfare).

While not having an adequate income is a problem for many people in the sample, so are expenditures for disability-related services and items. Persons in the sample are much more likely than others to have out-of-pocket costs relating to their disability that are not covered by any public or private plan (45.1 compared with 33.7 per cent). This problem decreases slightly with age, whereas it increases slightly for other persons with disabilities (Table 6).

Table 6. Proportion with out-of-pocket expenditures for disability-related services and items not reimbursed by any public or private plan.

AGE GROUP	SAMPLE	OTHERS WITH DISABILITIES
15-34	50.4	31.5
35-54	44.4	35.0
55-64	45.4	37.6
65 +	41.3	38.8
TOTAL	45.1	33.7

Concerning sources of income, people in the sample are much more likely than others with disabilities to be receiving social assistance, pensions or benefits from a public or private plan because of their condition (38 compared with 23.5 per cent).

Some 20.1 per cent in the sample receive welfare,³⁰ nearly triple that of others with disabilities (7.8 per cent). The sample is also more likely than others to be receiving the Canada Pension Plan disability benefit (15 compared with 8.5 per cent).³¹

Several respondents felt that individualized funding would be a way of addressing their need for income to offset the costs of services and items needed for disability. One individual advises voluntary organizations who are attempting to address financing issues, "Scrap the idea of having telethons. Telethons make the individual feel guilty about their situation". Several respondents indicated that the government has a lead role to play in ensuring people have the necessary funds for disability-related supports.

Employment

Several respondents commented on the importance of employment for their

personal well-being. One individual hopes to find a part-time job, not only for the money it will bring but also because it will help her out of her room where she lives alone. Another respondent hopes to start her own business. One wants to start a publishing company. A male interview respondent wants a job as a secretary. A respondent who receives FBA believes people on that system should be given jobs rather than being forced into relying on income assistance for years on end. "They should create jobs for us rather than keeping us on FBA," she said. "Instead we are left at home without skills and opportunities to better ourselves." Another said, "People with disabilities should not be forced into dead-end jobs and into sheltered workshops as employment options." One determined individual currently taking courses said, "I can't go to school forever. I have to go to work. I will try to get work here, but if that isn't possible, I will go somewhere else." She feels it is important that governments focus on creating a support system and other policies that will enable people to find jobs and keep them. Another respondent said one of the hardest things about getting older is finding work. He said, "unsheltered businesses don't hire people with disabilities." He would like to sell wheelchairs, but figures he will probably not get the chance to do so.

Working age people in the sample are much less likely than others with disabilities to be employed (28.3 compared with 48.4 per cent).³² For all persons with disabilities, the likelihood of employment decreases with age. However, this is particularly true for the sample. Only 8.6 per cent aged 55 to 64 have jobs.

Some 9.5 per cent of people in the sample who have jobs are self-employed (alone or in a partnership). This is also true of 11.7 per cent of others with disabilities who are working. Among people not in the sample who are working, persons aged 55 to 64 are most likely of all to be self-employed (21.6 per cent). This also appears true for the sample group, although the total number of older workers in the sample is very low and the data may not be reliable. Middle age workers in the sample, however, are much more likely than young workers to be self-employed (14.3 compared with 3.4 per cent).

Most people in the sample (69.3 per cent) are considered "persons with disabilities" for the purpose of federal employment equity legislation. However, as they age, they are less likely than others to "fit" within that legislative definition.³³ The decreasing likelihood of being covered by federal employment equity provisions may be due to extended periods of time that older people in the sample are out of employment. This is a factor that can remove individuals from the labour pool of people considered to be actively seeking work. They are considered extraneous to employer decisions about hiring and to labour market statistics, such as labour availability data.

Individuals in the sample who are working for salaries or wages are under-represented in management positions. However, they are relatively well represented in professional and semi-professional positions. They are nearly twice as likely as other workers with disabilities to be clerical workers.

Concerning labour market discrimination, working age people in the sample are

more likely than others with disabilities to feel an employer has refused them a job in the past five years because of their disability (13.2 compared with 7.5 per cent). Those most likely to feel they have been discriminated against in this way are between 15 and 35 years of age, 18.2 per cent this age believing they have been refused employment. Those in the sample least likely to feel an employer has refused them work because of their disability are aged 55 to 64, a finding that is also true for other people with disabilities. This finding may reflect actual decreases in employer discrimination towards older persons (which is unlikely), or the higher tendency of young adults to ascribe problems in finding work to employer discrimination rather than to other factors.

Participation in community activities

Interview respondents indicated that having opportunities to get out into the community to do things is important to their well-being. For one respondent, this means participating on several volunteer boards. For another it means working with like-minded individuals trying to create better community support options.³⁴ One individual takes pleasure in occasional trips on a river boat. For another it means simply going out, visiting others and attending community events such as sporting matches.

Statistical data on what people do in their spare time create a picture of greater social isolation and disconnectedness from activities in the community for people in the sample. This situation generally worsens as people get older.

For example, people in the sample are twice as likely as others never to go shopping (23.8 compared with 12.1 per cent). More than half the seniors in the sample never go shopping (56.1 per cent).

Those in the sample are much less likely than others to participate in religious and related activities (44.4 compared with 60.6 per cent); only 37 per cent of seniors in the sample ever do so. A mere handful of seniors in the sample (3.1 per cent) engage in volunteer activities compared with more than one-quarter of those aged 15 to 34.

Moreover, as individuals in the sample get older they are less likely to attend social and cultural events such as spectator sports, concerts, plays and movies. Fewer than one-third of seniors in the sample ever do so (32.7 per cent) compared with 77.9 per cent of adults in the sample younger than 35. Only 7.6 per cent of seniors in the sample go to museums, historic sites, libraries or art galleries (compared with 31.1 per cent of other seniors with disabilities and 55.6 per cent of those in the sample younger than 35. Fewer than four per cent of seniors in the sample take courses or attend seminars, compared with nearly one-third (29.8 per cent) in the sample aged between 35 and 54.

Freedom from violence and abuse

Several interview respondents indicated that violence and abuse are breaches of well-being. For example, one individual who was interviewed expressed significant concern about his personal safety and security on the streets. In his view, the poor economy is making people increasingly desperate for money,

leading some to victimize others to obtain it (e.g., by mugging). As a person in a wheelchair, he feels vulnerable to this form of harm and has been accosted on several occasions. Two other respondents became visibly agitated and shaken when asked whether they had ever lived in an institution. They indicated strongly that they did not wish to speak about the subject. Another respondent indicated she was nervous about the possibility of support workers overhearing what she was saying to the interviewer.

Statistical data on violence and abuse against persons with cerebral palsy are scarce. Research indicates, however, that violence and abuse against persons with disabilities is more widespread than had been previously thought, taking a number of forms.³⁵ The statistical analysis conducted for the present report found that persons in the sample are more likely than others to say one of their disabilities was caused by violence or abuse (2.8 compared with 1.9 per cent). Most of these people have ongoing difficulties with learning or memory, or have been labelled as mentally handicapped, or with a learning disability or with a mental health problem.

Control in decision making

Several respondents indicated that exercising personal control in decisions is essential to their personal well-being. One reflected with regret on a time in his life when he had let go of his control. His parents warned that the special school system was breaking his spirit and that he was not his usual self, a message he ignored for several years. He eventually realized the problem and left the school, now advising young people not to allow others to "put you in place". Another respondent emphasized the same point: "Make sure you are in control, not others".

Realizing people with cerebral palsy are at risk of losing personal control, one interview respondent advised service providers to "Listen to people with disabilities and help us in whatever way ... needed. Do it my way rather than [your] way. Go along with my wishes." She recognizes service providers may have difficulty doing so because "certain things take longer. Often they don't have time because they have other people to take care of. It's not all their fault." However, another respondent was less patient. "Make them [service providers] realize that this is your life," she said, "and that you want as much control as possible. Get the providers to respect your wishes and to get things done in the way that you want them done, not the way that they see fit". Yet another respondent said, "Listen to the person to get things done in the way they want, not in the way you, the service provider, want it to be done". Another advised service providers, "Don't try to steer people ... Encourage people to make their own decisions and encourage them to take the freedom to make choices."³⁶

Overall, persons in the statistical sample, like others with disabilities, feel in control of the decisions that affect their everyday activities. Fully 88.9 per cent indicate they make most or all such decisions (93.2 per cent among others with disabilities). However, the sense of personal control increases slightly for people in the sample as they age. For instance, 81 per cent of those aged between 15 and 34 feel they make most or all of the decisions that directly affect them, a

figure that increases to 96.6 per cent among people aged 65 and older. Age-related increases in decision making control are not as noticeable among others with disabilities.

One individual who was interviewed expressed frustration at having to schedule her life according to the availability of service workers (i.e., to be put to bed when they are available; to eat when they are available; to go to the bathroom only when an attendant can come; to receive physiotherapy at a clinic that is miles away from where she lives). She sees an individualized approach to funding as a model that will give her more control in decisions and arrangements concerning the support services she needs.

VIII. Policy Implications

When asked how the OFCP, its affiliates and governments can better respond to the issues people with cerebral palsy face as they get older, interview respondents provided comments that were somewhat general in nature. In part this may be due to the fact that many of the respondents were only beginning to think through issues relating to aging and had not yet given the policy implications much consideration. However, these data do provide some constructive options for the organizations and government to consider. As well, a number of policy implications can be teased out of the other interview and statistical data.

Implications for the OFCP and its affiliates

As they get older, people with cerebral palsy are contending with a wide range of issues. This fact alone suggests the importance of OFCP and its sister organizations adopting a holistic response to issues of aging. In the words of one respondent, "Look at the overall picture. Don't just look at cerebral palsy. People with cerebral palsy have a lot of other disabilities like arthritis, psychiatric illnesses and visual impairments. Realize it's not just needs connected with cerebral palsy; there are other needs, too."

Other respondents recommended the OFCP and other organizations become more involved in direct service delivery. Suggested avenues include helping individuals offset the costs of assistive aids and devices. "Be there to help if anyone needs it - like equipment," said one respondent, "They can't afford it on their own." Others suggested the organization could play a role in providing services that help keep people with cerebral palsy active, especially in their later years. One respondent expressed interest in working with OFCP to develop such programs.

Several respondents suggested that OFCP could play a more direct role informing others, such as health care professionals, about issues of aging as these concern people with cerebral palsy. Some suggested OFCP could serve as a clearing house of information about housing and other support options available to people in their local communities.

Indeed, the provision of information may be a practical and affordable line of

activity the OFCP and its affiliates could pursue. Themes that could be addressed through informational products could include the importance and forms of good nutrition, the potential role and benefits of physical activity in the lives of people as they get older, and information on the risks of dependency on medications, unnecessary technologies and dietary supplements. Positive examples of how people are thriving later in life might also shed important light on the subjective determinants of well-being. By promoting greater access to opportunities for learning and self-development in community programs, the organizations could help individuals maintain a positive attitude towards life.

The organizations may also be able to address the social determinants of well-being. For example, they could find ways of helping people with cerebral palsy strike up relationships with others in the community. The organizations could add their voices to those advocating greater availability and better access to support services, transportation and to community programs more generally (e.g., recreation and cultural programs). The organizations may also be able to play a role consulting with the private sector on effective ways of integrating persons with cerebral palsy in the workplace, addressing in particular the challenges older people face in trying to move into employment or hold onto their present jobs. The organizations could research, provide information, form partnerships with financial institutions and support networking for people interested in starting their own business. As well, the organizations could explore ways of providing support services that will reduce the risks of violence and abuse, and that will ensure these problems are effectively addressed where they occur. The organizations could also explore ways of ensuring people with cerebral palsy have personal control over the decisions that affect their everyday activities.

If the organizations opt not to play a direct role in helping finance the costs of disability-related aids and devices, they could consider lending support to other organizations requesting governments to improve cost-coverage for those items. The organizations could also explore individualized approaches to financing disability-related support requirements, could perhaps pilot such an approach, or could work with the government to explore the feasibility of implementing such a model on a systemic level. As well, there may be opportunities and politically attractive grounds for exploring the adequacy of current income support arrangements, and for devising program solutions to basic incomes that are often very low.

Implications for government

A recurring policy direction interview respondents want governments follow is to stop the process of financial cutbacks to persons with disabilities and to the support services they require, including health services, social services and programs that provide aids and devices. In fact, many of the recommendations emphasized the need for governments to strengthen instead of eroding their present financial commitments.

For some respondents, however, the issue is not so much the need for more resources as how current resources are being used. Several pointed out the

need for programs that are more enabling and that will help people with cerebral palsy participate in the mainstream economy instead of in segregated work programs, dead end jobs or no jobs at all. Needed changes that were cited are in the areas of job training and placement services, income programs that create incentives and support for people who want employment, and disability-related support programs (e.g., for attendant services and assistive device) that are more available to people and which could help some move into the open labour market instead of relying exclusively on income support and sheltered labour market programming.

Several respondents mentioned the now well-known need for better transportation services (urban and inter-city). Others spoke of the need for more accessible transportation, one respondent pointing to the need for better linkages between transportation and other support services. In the words of this person, "Many busses and trains can't be boarded unless someone is with you. But you don't always have someone to get away for a day or a couple of hours."

Some respondents encouraged governments to continue in policy directions to which they are already committed, such as deinstitutionalization. Some others, however, look to institutionalization in the future as the only option available to them to meet their social and support needs as they get older. Alternatives to institutions for people currently living in the community clearly need to be explored.

Other government policy directions for which there was support in the interviews include ones that would make workplaces and employer hiring practices more open to persons with cerebral palsy and other disabilities, particularly older persons. Support was also voiced for policy directives aiming to make community facilities and programs more accessible.

IX. Summary

For people interviewed in this research, growing older means coming to terms with various losses, including the loss of functional abilities and the loss of independence in everyday activities. Physical complications become more commonplace as individuals get older, and regular pain and discomfort become facts of life for many. Aging means going through key life transitions that define people's lives, in some cases bringing greater independence, and in others, less. However, as happens for many people as they get older, aging for people with cerebral palsy can mean new opportunities for finding satisfaction in life.

Physical factors that interview respondents said help promote their personal well-being include familiar health precautions, such as good nutrition, physical activity, caution in the use of medications, and the avoidance of behaviours that place physical health at risk (e.g., smoking and excess alcohol consumption). Access to quality health-related services was given as another important condition for maintaining personal well-being. Generally it would seem that nutritional intake becomes poorer for individuals who were sampled as they age.

They also become less physically active, more reliant on medications and more prone to some health-risk behaviours such as smoking.

Subjective factors that promote a sense of well-being include maintaining positive attitudes and outlook, being open to new learning and experiences, and accepting one's situation without giving into passivity and fatalism. The middle years of adulthood seem to be the most emotionally difficult for persons in the statistical sample.

Social factors that contribute to personal well-being include respect from others, having relationships with others beside those who are paid to care, access to support services to assist with everyday activities, and access to the aids and devices that are required for physical health and independence. Generally, these become more serious problems for the people who were sampled as they get older. Informal networks of family members, friends and neighbours are increasingly important in the lives of persons in the statistical sample as they get older, both for emotional support and for help with daily activities.

Having an adequate income was cited as another important condition, the lack of which compromises well-being. Low incomes are widespread in the statistical sample, a problem that tends to ease somewhat as individuals reach retirement age. Opportunities to socialize, to make a contribution to society and to provide for personal financial security through employment was given as another important determinant of well-being. However, lack of employment is a major problem for those sampled, and becomes an even more difficult challenge in the ten years before retirement age.

Respondents also spoke of the importance of access to community programs and opportunities. Generally, however, participation in such activities decreases with age. Respondents identified having personal control over the decisions that affect their everyday lives as crucial to their well-being. On a positive note, the sense of personal control seems to increase with age among those sampled.

Policy recommendations for OFCP, its affiliates and governments underscore the need for stakeholders in the well-being of persons with cerebral palsy to become more informed about their needs as they age. Community organizations need to adopt a holistic approach, recognizing that aging cannot be reduced to considerations of cerebral palsy alone, but involves many other disabilities and concerns as well. Respondents saw an important role for these organizations to play in information sharing, in developing programs to respond to specific needs, and in working with other groups to pursue changes more systemically. Respondents felt governments need to maintain and strengthen their present commitments to people with cerebral palsy, exploring new ways of addressing needs while strengthening individual independence and participation in society.

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2. See Ontario Federation for Cerebral Palsy (1993) Health, Aging and Cerebral Palsy, Ontario Federation for Cerebral Palsy (1993) Aging with a Lifelong Physical Disability: A Self-Help Guide.

3. See The Roeher Institute (1995), Social Well-Being: A Paradigm for Reform, North York.

4. Persons with cerebral palsy cannot be identified as a specific sub-group using HALS 1991.

5. The social well-being framework was not used in a rigorous way to organize the research findings. Instead, the categories that emerged during the interviews were used as the organizing scheme.

6. None who were interviewed were married or living with intimate partners.

7. 31 and 31.9 per cent of those in the respective groups who have ever legally married are now separated or divorced.

8. Among the people interviewed for the research, 61.5 per cent were living alone.

9. Among those interviewed, 64.3 per cent said they had attended technical school, community college or university.

10. Those indicating low literacy skills are those who say a) their skills are below the three on a five-point scale (five representing "excellent" and one representing "poor") or b) who say their reading and writing skills are not adequate for their daily life.

11. The HALS severity scale represents the degree of activity limitation. Survey respondents classified as having a "severe" level of disability have a higher degree of activity limitation than other survey respondents.

12. One individual who was interviewed indicated that she actually has more control over her bodily movements than she had when she was younger.

13. People classified as in the HALS "other" disability category include persons with ongoing problems with learning or memory, persons identified by professionals as having a learning disability or mental handicap, persons with a psychiatric disability or who have been labelled by a mental health professional and who feel limited by that label.

14. Exceptions to this rule are in the areas of mobility and agility. Even early in life, persons in the sample are likely to have such activity limitations.

15. e.g., washing, dressing, using the toilet.
16. This issue is examined in more detail in Section VII.
17. Issues of loneliness and friendships are examined in Section VII.
18. Most of the people who were interviewed had lived in an institution at some point in life.
19. The HALS 1986 sample was constructed using all respondents on screening question A2OC who were classified as having conditions that fall within the ICD9 340-349 range. The weighted sample size was 38,910 persons.
20. 75.7 per cent indicate they do participate in physical activities during leisure.
21. Turk, M.A, Overeynder, J.C. and Janicki, M.P. (1995), Uncertain Future: Aging and Cerebral Palsy - Clinical Concerns, New York State Developmental Disabilities Planning Council.
22. Such services include those of dentists, nurses, chiropractors, psychologists, social workers, counsellors or mental health workers, therapists, speech and language pathologists, family doctors or general practitioners, and medical specialists.
23. Information on patterns of health care service use was not released for HALS 1991.
24. Seniors in the sample are also less likely to say that they never feel "on top of the world" (only 18.7 per cent compared with 31.3 per cent of the sample over all). One-fifth (19.9 per cent) in the sample between 35 and 54 years of age say among seniors. Age-related changes in feelings of depression and unhappiness are not as noticeable among other persons with disabilities.
25. Among those surveyed for HALS, 11 per cent in the sample aged 35 to 54 were enrolled at school, college or university when the survey was conducted. Among others with disabilities, only 5.3 per cent were enrolled.
26. Only 14.8 per cent of other seniors with disabilities never visit with others, compared with 8.7 per cent among other people with disabilities taken as a whole.
27. 19.9 per cent of seniors sampled never talk to others by telephone in their spare time, compared with 11.9 per cent in the sample as a whole. For others with disabilities, only 10.1 per cent aged 65 and older never use the telephone for social contact, 7.4 per cent among people with disabilities outside the sample over all.
28. Among those needing help, people in the sample are increasingly more

likely as they get older to indicate they have all the help they require. Only 33.3 per cent of those aged 15 to 34 needing help say they receive enough, compared with 76 per cent of those 65 and older. This is not the case among others, roughly half of whom need more help than they receive regardless of age.

29. Among those in the statistical sample, 70.1 per cent have total incomes of less than \$15,000.

30. Among those interviewed for the research, 78.6 per cent were receiving welfare or Family Benefits Allowances.

31. Those in the sample most likely to be receiving the CPP disability benefit are aged 55 to 64; 32.6 per cent of this group receive the disability benefit compared with only 20.6 per cent of others this age. In contrast, those in the sample most likely to be receiving welfare are between 15 and 34 years of age (38.8 per cent). People in the sample are less likely to receive welfare as they age (e.g., only 15.4 per cent of those aged 55 to 64 receive welfare).

32. Only 14.3 per cent of working age people who were interviewed for the research were working for pay.

33. For instance, 76.4 per cent of the persons sampled who are between 15 and 35 fall within the definition, as do 59.3 per cent of other persons with disabilities this age. Yet only 46.8 per cent of the sample who are between 55 and 64 fall within the definition -- a decrease of nearly 30 percentage points compared with younger adults. Some 48.6 per cent of others the 55 to 64 age range continue to be covered by the act, a decrease of only 10.7 per cent compared with their younger counterparts.

34. 62.5 per cent of those interviewed were involved with some form of volunteer work.

35. See, for instance, the Roeher Institute (1995), *Harm's way: The many faces of violence and abuse against persons with disabilities in Canada*, North York.

36. Another respondent alluded to the risks that go along with personal control, advising younger people to "Take time to think about your options before you make a decision. Otherwise you may live with a lot of regrets."