

# FINAL EVALUATION REPORT

Self-Managed Attendant Services  
in Ontario:

Direct Funding Pilot Project

March, 1997



...a resource centre

CENTRE FOR INDEPENDENT LIVING IN TORONTO (CILT), INC.

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## Executive Summary

This report is an evaluation of the Self-Managed Attendant Services: Direct Funding Pilot Project in Ontario. One hundred and two individuals were provided with direct funding through the Pilot to hire and manage their own attendant services. The Project was led by a consumer-government partnership, and funding was provided through the Ministry of Health. The Centre for Independent Living in Toronto (CILT) acted as Project Administration. Eight other Independent Living Resource Centres (ILRCs) throughout Ontario joined CILT to provide supportive resources to self-managers on an as-needed and as-requested basis.

The results of the evaluation point to a number of successes of this Pilot initiative in terms of:

- establishing a consumer-driven partnership;
- encouraging participation in the Pilot Project;
- securing choice, flexibility, and control over attendant services;
- fostering social and economic participation;
- creating effective employer-employee relationships;
- enabling available and appropriate supportive resources;
- promoting a responsive Pilot Project;
- ensuring cost-effective provision of attendant services.

A “consumer-driven” partnership was designed to maximize consumer involvement in the initiative. The Project Steering Committee included a majority of persons with disabilities who use attendant services, and the involvement of Independent Living Resource Centres throughout Ontario ensured an ongoing involvement of the consumer movement. This Pilot is an excellent example of what a public and non-profit sector partnership can accomplish.

The Pilot aimed to ensure that a wide representation of persons with disabilities would have the opportunity to become self-managers. This was accomplished for the most part, especially in relation to region of the province, rural/urban location, and a range of living arrangements of participants. However, women and persons of ethno-cultural minorities were somewhat under-represented. Women made up 46% of the participants in the Pilot Project, and 5% of the participants surveyed identified themselves as a visible minority. No one identified herself or himself as aboriginal.

Providing people with disabilities who use attendant services with the funding to hire and manage their own staff changes the usual relationship between consumers and attendants. With self-managed direct funding, the participants in this Pilot became the

employers of their attendants, in most cases for the first time. Both self-managers and attendants pointed to the increased accountability to persons with disabilities that this change in the employer-employee relationship brought, and to the greater degree of mutual respect it fostered. As well, attendants who had worked in other service systems reported much higher degrees of job satisfaction in working directly for people with disabilities.

Direct funding provided to the participating self managers more control, choice, and flexibility in attendant services than they have had in the past. They pointed to the many ways in which this made a difference in their lives in terms of increased self-determination in all aspects of their lives, reduced vulnerability, greater independence, a stronger sense of self-esteem, more fulfilling personal relationships and increased social participation. As one participant put it,

*"It always seemed unjust to think I could hold an important position in the educational community, buy and sell personal property, look after personal funds, move to another city, be happily married for over ten years, but I couldn't decide for myself when I had to go to the washroom. With this program I am truly in control of my life."*

A number of self-managers reported increased opportunities for paid employment and career advancement as a result of the flexibility that greater control over attendant services brings.

The Pilot Project resulted in the development of a number of supportive resources that many self-managers found extremely helpful and that will remain an important legacy of this Project. The manuals prepared by CILT to assist self-managers in all aspects of hiring and managing attendants were considered invaluable by most self-managers. CILT also developed administrative and reporting procedures for self-managers and provided back-up support in this regard. For the most part, the other Independent Living Resource Centres were also considered to be very supportive, although some self-managers felt that certain centres were not as informed as they could be.

Responsiveness to the individual needs for disability-related and management support was a key feature of the funding mechanism under this Project. This enabled self-managers to hire attendants in areas where they had not been able to obtain attendant services in the past, and thus promoted greater equity in the delivery of such supports. The responsiveness to individual need also permitted self-managers to tailor their expenditures to their actual requirements. Indeed, over half of the participants who began self-managing in 1995 have spent less than their approved budget.

Based on the evidence from this Pilot, direct funding for attendant services appears to be a very cost-effective alternative to conventional service delivery of attendant services, in three respects. The administrative savings appear to be very substantial, with the cost of delivering one hour of attendant service under the Pilot being 30% to 50% less than the usually available alternatives (Outreach and supportive housing — SSLUs). By substituting lower-cost attendant services for Home Care services, participants in this Project contributed to substantial savings in the cost of in-home support. Finally, the flexibility with which self-managers could arrange their schedules of attendant services led to reduced use of acute health care facilities, on an average per capita basis, and reduced stays in long-term care and rehabilitation facilities.

In order to sustain what this Pilot Project has clearly accomplished a number of challenges will need to be faced.

First, criteria for participation in self-managed direct funding appear to need both clarification and possibly review. The contract stipulated that self-managers who resided in Support Service Living Units (SSLUs) prior to the Pilot had to make alternative living arrangements within three months or demonstrate that their continued residence would not prevent another person from receiving the SSLUs' services; this criterion was not uniformly interpreted by self-managers. "Self-management capacity" as defined for the purposes of this Project might unnecessarily exclude individuals who may need assistance in self-management because of a lack of management skills or because of a deteriorating condition. Self-management, at least in theory, does not appear to be at odds with a recognition of the need for support. The notion of "accommodating" the needs of persons with disabilities so they can benefit from opportunities would seem to apply as well to the opportunity to manage direct funding for attendant services or other disability-related supports.

Second, there were a number of issues raised by attendant workers through the course of the evaluation, by self-managers, and by representatives of ILRCs that suggest a need for greater collective attention to such issues. Concerns about conditions of work, rates of pay, supports in training, and developing an ongoing capacity to address attendant worker needs were identified. Some ongoing capacity to address these issues in the context of a system for self-managed direct funding could be considered.

Third, the financial accountability of self-managers was questioned in only a couple of instances. While a more strict monitoring system does not seem necessary, further clarification of the conditions under which self-managers can expend funds is probably required.

Fourth, in order to strengthen and maintain the ongoing capacity for individuals to self-manage attendant services it will be important to continue with existing supports and to enhance them in specific ways. Some more proactive review of budgets and support

arrangements may be needed to assist those who face deteriorating conditions or fluctuating requirements, or who require more assistance in self-managing. Many self-managers desire additional workshops on various aspects of self-managing, and for additional efforts to enable self-managers to network among themselves. For those who are revising their budgets, or for others who may apply to such a program in the future if it were expanded, it should be anticipated that additional support in preparing applications and budgets will be needed. This kind of support is required by some self-managers prior to entering a selection interview.

Finally, a number of systemic issues external to this Pilot pose challenges in ensuring choice, flexibility and control for people who use attendant services. Housing that is physically accessible and affordable is scarce across the province. A number of the participants encountered difficulties making alternative housing arrangements. Lack of accessible, affordable housing in their communities led some potential applicants who currently live in supportive housing not to apply and one individual who was selected not to participate. Concerns about the affordability of housing are related to the general exclusion of people with disabilities from the labour force. In addition, many facilities and programs still do not accommodate people with disabilities, and even with the attendant services made available through this Pilot Project, many have unmet needs for assistance from others. Several participants also reported that they lack adapted equipment, environmental modifications and assistive devices that would enable them to participate more actively in the economy and in their communities. Lack of accessible, reliable, and affordable transportation, for example, persists in urban areas and is of particular concern in less densely populated areas of the province.

In summary, the collaboration of the Independent Living movement in Ontario and the Government of Ontario has been impressive throughout the design and implementation of this Pilot Project. Through their efforts they have demonstrated that direct funding for people with disabilities is a viable and cost-effective alternative for the funding attendant services. They have given to people with disabilities an opportunity to demonstrate that they can manage their own supports in ways they deem most appropriate given their own life goals and needs. The result has been that many of the obstacles and inequities that people with disabilities face have been substantially reduced, and their social and economic participation have increased significantly. This Project makes eminently clear that entrenched social, economic, and physical barriers are not immune to change; nor is the control that others have often imposed upon people with disabilities. How public funding and publicly funded services are delivered *does* make a difference in the opportunity for people to exercise their rights, and thereby improves the quality of their lives.

## Introduction

The demand for attendant and other disability-related services in the community is growing. The policy shift towards deinstitutionalization, the increasing number of senior citizens, and the burgeoning disability rights movement — nurtured by the equality guarantees to people with disabilities in the *Canadian Charter of Rights and Freedoms* — have all contributed to this demand. Based on Statistics Canada data collected in 1991, over 1.2 million people in Canada who do not live in an institution require at least one of the services provided by attendants under this Pilot Project.<sup>1</sup>

In Ontario as in most other jurisdictions in Canada, agencies currently manage and deliver almost all available attendant services. Given the importance of these services for living an active and fulfilling life in the community, it is not surprising that consumers have expressed an interest in ensuring that service providers are accountable to them. Meanwhile, the demand for attendant services outstrips supply, even though lack of access to attendant services inhibits full participation in the economic and social fabric of communities and can compromise health and well-being. The shortage of these services in sparsely populated and rural areas of Ontario persists. Some residents of Ontario have been on waiting lists for existing attendant services for several years.

The independent living movement and its allies believe that certain aspects of the conventional agency-managed service delivery system could be improved. In this system, professionals assess needs, ration resources and determine how and when the services will be provided. People with disabilities want to make these decisions themselves. They feel that they are well-positioned to determine what they need. Given the uneven availability of these essential services, consumers maintain that it is in their collective interest to use the available resources efficiently and equitably.

This is the final report of the evaluation of the Self-Managed Attendant Services in Ontario: Direct Funding Pilot. The Roeher Institute was selected through a competition to evaluate this Project. The **overall purpose of the evaluation** was:

*to evaluate the capacity of the direct funding model implemented in this Pilot Project to address, in a cost-effective manner, consumer demands for flexibility, choice and control over attendant services.*

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<sup>1</sup> The source for this figure is the Health and Activity Limitations Survey conducted by Statistics Canada in 1991. It is most likely conservative estimate, as the population has aged and increased since 1991. See appendix describing the methodology for more detail on how this figure was calculated.

This Pilot Project was designed to respond to consumer demands for control and full responsibility as employers over their attendant services by testing self-managed direct funding with a group of about one hundred people. It was established through a partnership of the Ontario Network of Independent Living Resource Centres, the Ontario Ministry of Health, and representatives of the disability community in Ontario. People with disabilities who require attendant services were involved in all aspects of the Project, including its design, governance and management. The Project was announced in June 1994 and it is scheduled to run until the end of March 1997.

The first section of this report describes the key features of the Pilot: its structure and organization; the policy framework that underlay its design and implementation; the application and selection process; the review process; the main activities and key responsibilities of those who self-managed their attendant services through this initiative.

The second section presents the findings. Section A evaluates the extent to which the Pilot was consumer-driven, and the effectiveness of the partnerships established as a result of the Pilot, are evaluated. Section B examines elements leading up to participation in the Pilot Project, and presents a profile of selected and non-selected applicants. Then, in Section C and Section D respectively, the ways in which the Pilot contributed to participants' sense of choice, flexibility and control and their participation in social and economic spheres are analyzed, and some ongoing challenges in realizing these goals are identified. Employer-employee relationships set up under the auspices of the Pilot are the focus of Section E. Section F examines how supportive resources made available under the Pilot Project were used and their effectiveness. Section G presents results pertaining to the responsiveness of the Pilot to individual need as well as the administrative and systemic responsiveness. The cost-effectiveness of the Pilot is assessed in Section H. Finally, conclusions reached as a result of this evaluation are presented.

This report also contains a number of appendices that provide valuable background to the Pilot and its evaluation. The methodology is reviewed in detail in Appendix #1. Appendix #2 presents the evaluation framework, including the specific objectives set for the Pilot and the indicators chosen to measure them in concrete terms. Appendix #3 provides an overview of the history of the Pilot Project's development. A map of Ontario, indicating the Ministry of Health regions, can be found in Appendix #4. A glossary of key terms used in the report is found in Appendix #5.

The Roeher Institute was assisted in conducting this evaluation by Ernie Lightman, who provided invaluable input in developing the methodology for evaluating the cost-

effectiveness of the Pilot, and by Randy Barrett, Mary Cernagoj, and Pat Israel, who conducted the bulk of the semi-structured interviews with self-managers. Michael Bach and Melanie Rock of The Roeher Institute conducted the other interviews and the participant-observation research undertaken for this evaluation. Melanie Rock analyzed the quantitative data. This report was prepared by Melanie Rock and Michael Bach.

## Description of the Pilot Project

This section of the report outlines the main features of the policies and administrative arrangements that have guided the implementation of the Pilot Project. It also presents demographic profiles of the self-managers selected in 1995 to participate in the Pilot Project, their attendants, and non-selected applicants.

### A. Structure and organization of the Pilot Project

From its inception, the Pilot Project has been governed by a Steering Committee. The Steering Committee is comprised of representatives from government (policy and operations), representatives from the Ontario Network of Independent Living Resource Centres, including the Centre for Independent Living in Toronto (CILT), and community representatives. The community representatives include people who use attendant services, of whom one is a senior citizen, and an individual who worked as an attendant for a number of years in a unionized environment. Various sub-committees, such as the Evaluation Sub-Committee, were formed to oversee particular dimensions of the Pilot Project.

CILT acts as the Pilot Administration. As a transfer payment agency, it manages and distributes funds allocated to the Pilot. The relationship between CILT and the provincial government is outlined in a contract that specifies each party's roles and responsibilities. The staffing arrangements made by CILT for the Pilot include a program director and an administrative coordinator position. Other CILT staff members have also devoted considerable energy to the Pilot.

While CILT, in its role as Pilot Administration, has taken a lead role in developing and implementing the Project, the other members of the Ontario Network of Independent Living Resource Centres have also been involved. From the outset, it was envisioned that these Centres, located in the various regions of the province, would be positioned to lend support to the Project. Representatives from all the Centres participated in the selection process and have been available to support individual participants in their transition to self-management.

Each self-manager entered a contract with CILT that specified their role under the Project; namely, sole responsibility for their attendant service arrangements and full legal liability as the employer of the attendants that they hired.

## B. Policy framework

The policy framework for the Project has three components: legislation, regulations and policy guidelines.

### Legislation

In the late 1980s and early 1990s, direct funding for individuals' disability-related services gained credence as a policy innovation (Egley 1994a; Egley 1994b; Roeher Institute, 1993 #183; Gail V. Barrington and Associates 1993; Kestenbaum 1992; Roeher Institute 1991; Lord 1988; Ontario Advisory Council for Disabled Persons 1988). However, the lack of legal mechanisms through which to flow funds to individuals has been encountered as an obstacle. In order to provide a legal mechanism for direct funding in Ontario, the *Ministry of Community and Social Services Act* was amended to allow for direct funding, subject to regulations (Ontario 1993).

While not specifically linked to this Project, the provisions of the *Regulated Health Professions Act* are critical for attendant services in Ontario more generally (Ontario 1991). People with disabilities organized so that the *Regulated Health Professions Act* would provide exceptions when a worker performs services that would otherwise be considered controlled acts in the course of assisting a person with his or her routine activities of living. When the *Regulated Health Professions Act* was first introduced, some of the routines typically performed by attendants, such as catheterization, were designated as controlled acts. This stipulation contradicted the independent living approach to attendant services, that attendant services are for activities that would ordinarily be done by individuals themselves, were it not for their disabilities. In other words, attendants function as the individual's "arms and legs."

### Regulations

Detailed regulations were filed in June 1994 to enable the direct funding provision in the *Ministry of Community and Social Services Act* to be put into practice (Ontario 1994).

These regulations define attendant services as assisting a person with:

1. turning in bed, lifting, positioning or transferring;
2. washing, bathing, showering, shaving or personal grooming;
3. dressing or undressing;
4. catheterization, emptying and changing a leg bag, using the toilet, urination or bowel routines;

5. breathing, or caring for a tracheotomy or respiratory equipment;
6. eating;
7. meal preparation, dish washing, laundry or other housekeeping tasks; or
8. essential communication.

The regulations specify that an individual may be eligible for direct funding if s/he:

- a. is at least sixteen years old;
- b. requires attendant services as a result of a permanent disability;
- c. requires the attendant services referred to in at least two of "1" to "8" and at least one of them is from "1" to "4" above;
- d. has attendant service requirements that have been stable over a period of at least one year;
- e. has service requirements that can be met while residing in his/her home;
- f. understands the nature of his/her disability and its impact on his/her ability to carry out the essential activities of daily living;
- g. is aware of the type of attendant services s/he requires and when, how much and how assistance should be provided;
- h. is capable of scheduling his/her attendant services as well as making alternative arrangements to ensure that his/her requirements are met in case an attendant worker is not available at a scheduled time;
- i. is capable of training or arranging for the training of, supervising, instructing and communicating with attendant workers;
- j. is capable of recruiting, hiring, and dismissing attendant workers;
- k. is capable of understanding and carrying out the responsibilities as an employer of one or more attendant workers;
- l. is capable of managing and accounting for the expenditure of funds that would be granted to him/her;
- m. is capable of evaluating the attendant services s/he would receive and communicating his/her evaluation; and
- n. is prepared to undertake the functions referred to in clauses "h" to "m" and to assume the responsibility and risks inherent in undertaking those functions.

### **Policy guidelines**

Guidelines were developed in the proposal for the Pilot. The proposal outlined the roles, responsibilities and aims of the Project. Drafts were widely circulated among consumers and government officials including Ministry of Health Long Term Care area offices.

The Steering Committee adopted a number of policies for the Pilot. For example, a policy was needed to guide the Pilot's response to applicants with private insurance settlements that include coverage for attendant services. The Steering Committee determined that, under the Pilot, participants with private insurance settlements received funding from government only as last payer. For participants with a lump sum settlement, this meant all their award had to be spent prior to becoming eligible for funding under the Pilot. Participants with an ongoing insurance benefit had to demonstrate that their attendant service requirements exceeded the benefit and were eligible only for funds to cover the difference.

Procedures for self-managers to follow in setting up their direct funding bank accounts underwent elaboration during the course of the Pilot. Self-managers were directed from the beginning to set up a separate bank account, but the Steering Committee also determined that these accounts should not bear significant interest and that banking card access should not be issued.

In order for the Project to be feasible, transfers to individuals cannot be regarded as personal income. Revenue Canada has confirmed the legality of this position in writing.

Under the Pilot, the relationship between self-managers and attendants was one of an employer-employee. Consequently, self-managers were required to make source deductions for income tax, Employment Insurance, Canadian Pension Plan (CPP) where applicable, and to pay assessments to Worker's Compensation where applicable to ensure coverage for their employees. Sufficient funds were budgeted for individuals to enable them to pay their employees' wages and these benefits, as well as the self-managers' administrative expenses (for example, book-keeping, banking, office supplies) and attendants' travel to work.

### **C. Application and selection process**

For individuals interested in becoming self-managers under the Pilot, the application process began with submission of a letter of intent to CILT. CILT mailed application packages to those who submitted letters of intent. In the three years leading up to the Pilot Project, CILT received 250 letters of intent. Five individuals in the Central East region and one individual in the Central West region served as a test group; they submitted their application forms in November 1994. After being interviewed by a selection panel, five of these individuals were selected for participation in the Pilot Project. On the basis of their feedback from this group, the application materials were modified somewhat and mailed in December 1994 to all others who had submitted a letter of intent. The cut off date for receipt of applications was 16 February 1995, by which time over 150 application forms had been received by CILT. From January to

April 1995, nine regional selection panels interviewed a total of 122 applicants and recommended to the Steering Committee whether or not the applicants should be selected. In total, the Steering Committee selected seventy-eight applicants in 1995.

It was envisioned at the outset of the Pilot that selected applicants would require an even spread of hours from 60 to 180, with mean of 120 hours per month. Instead, the mean number of recommended hours was 140. Consequently, instead of selecting 100 participants as originally planned, the funds were judged to be sufficient to select seventy-eight. Funds estimated to be sufficient to select an additional twenty-two individuals were allocated to the Pilot in the spring of 1996. At the time of the announcement, the status of applications and letters of intent was as follows:

- Two individuals had already been recommended but had not begun participating because of limited funds;
- Eighteen applications were on file because they had arrived after the deadline;
- Fifty-six had submitted letters of intent.

Those whose applications arrived after the deadline, those who had submitted letters of intent, and eligible applicants not selected in 1995 who expressed an interest in re-applying were invited to submit applications. In addition, a telephone interview was granted to an individual who had not been selected in 1995 and who had requested and been granted a second interview. An individual who was not selected in 1995 because of private insurance coverage that was estimated to be sufficient for one more year was asked to update the application. In total, seventy-six applications were received, fifty were interviewed and twenty-five were selected in 1996.

Project staff at CILT examined the application packages to verify accuracy and completeness. Those whose application forms were incomplete or inaccurate were offered an opportunity to revise their application.

The selection panels typically consisted of a CILT staff member, a representative of an Independent Living Resource Centre in the applicant's region and a community representative. The selection process relied on peer validation of both applicants' needs for attendant services and their capacity for self-management.

At least two of the three members on the selection panels were users of attendant services. At least one person and often two of the three were from the same region as the applicant. Typically, at least two members of the panel were of the same gender as the applicant. The validation process was standardized by developing a measure of self-management skills (see Findings section for further details).

All selection panellists went through a training process before interviewing any applicants. After the test group interviews, but before the bulk of the interviews began, CILT conducted a workshop in Toronto for selection panellists representing ILRCs across the province. The eligibility criteria, the aims of the Pilot Project and the role of the selection panels were reviewed at this workshop. Selection panellists representing the community were given training at the local ILRC or interview site prior to the interviews. The person who trained these panellists reviewed a sample application form using the notes for the trainer, both developed by CILT, in order to point out key elements of the application and interview. To provide panellists with a sense of some of the average times and costs involved, they received a copy of the guidelines to checking an application developed by CILT. They were also introduced to the form in which the results of the interview were to be recorded. On average, it took one hour to train community panellists. All panellists signed an agreement to ensure confidentiality and no conflicts of interest.

Thirty-one people who submitted an application subsequently withdrew. Two people withdrew after being accepted, one because of the difficulties in finding accessible, affordable rental accommodation and the other because this individual's long-time attendant would not consent to becoming an employee under the Pilot.

#### **D. Review process**

The Steering Committee anticipated that a review process could be required to respond to questions regarding its selection decisions, and so invited all non-selected applicants to request a review, if they felt it was warranted. A Review Sub-Committee of the Steering Committee was struck to develop and implement the review process.

An explanation of the procedures for requesting a review was sent to all non-selected applicants. The notification indicated:

*"The review group will look at all of the documentation, examine the panel process and decisions, interview the panellists, other parties as warranted and the applicant by tele-conference and make a determination on an individual basis about whether the applicant was treated fairly."*

The notification also advised non-selected applicants that anyone interviewed a second time would meet with a different selection panel.

Nine requests for a review were received in 1995. The committee reviewed application materials, selection panel decisions and additional information provided by applicants.

One person withdrew from the process. The decision not to accept two candidates was upheld, one candidate who missed the deadline for receipt of application materials was interviewed, two candidates were accepted contingent upon accepting the number of hours approved by the Steering Committee and an opportunity for another interview was granted to three candidates. Those interviewed as a result of this process were advised that, if selected, they would be put on a waiting list.

Two requests for review were received in 1996. The review committee found that there was insufficient basis to re-interview one of the applicants, although the committee did recommend that CILT provide assistance to the applicant in obtaining more in-home services through other sources. In the other case, the committee is awaiting further information and may recommend the individual for selection. The committee has suggested that this individual's name be added to the list of eligible candidates and ranked according to the self-management score, with a possibility of a second interview.

### **E. Self-managed attendant services under the Pilot Project**

Selected applicants were notified by mail that they would have an opportunity to self-manage their attendant services. They were asked to confirm their participation in the Pilot Project by signing a contract with CILT. Upon receipt of the signed contract, CILT issued their first direct funding advance.

Before beginning, they had to deal with some administrative matters. They had to:

- extend their home insurance to \$2 million to cover liability for an employed domestic;
- open a separate direct funding bank account;
- recruit staff, and in many cases, orient and train them;
- make book-keeping arrangements; and
- register with Revenue Canada for a business number.

Based on interviews conducted for this evaluation, it appears that most self-managers have contracted a book keeper. Many have also made arrangements with a payroll service. Some self-managers maintained their own records for the first few months in order to ensure they understood all the requirements, and others continue to perform the book-keeping and payroll tasks themselves.

In addition to the demands during the transition period, self-managers were responsible for managing their attendant services on an ongoing basis. The ongoing work included:

- monitoring funds;
- preparing quarterly reports for the Pilot Administration on their usage of funds;
- personnel management, including scheduling, evaluating, and in some cases, terminating and recruiting replacement staff;
- recording hours worked for bi-weekly payroll preparation;
- monitoring payroll deductions and submitting them monthly to Revenue Canada; and
- signing cheques.

The ongoing work varied in intensity from one self-manager to another and from one time period to another.

The number of hours covered by the Pilot varied in relation to individual need, up to the maximum of 180 hours per month or its cash equivalent. In devising their annual budgets, applicants were directed to take periodic chores and seasonal fluctuations in their schedules into account. Some individuals have requested a revision of their original allocated hours on the basis of changes in their circumstances. For example, two individuals had a baby and requested additional hours for nurturing assistance; these requests were approved. A claw-back policy has been put in place to reduce surplus for individuals who have used fewer than their allotted hours during a quarterly period, and a contingency fund has been established to provide for service usage exceeding the individual's regular budget.

## Findings

The Terms of Reference for the evaluation of the Self-Managed Direct Funding Pilot Project, identified a number of desired outcomes related to:

- establishing a consumer-driven partnership;
- encouraging participation in the Pilot Project;
- securing choice, flexibility and control over attendant services;
- fostering social and economic participation;
- creating effective employer-employee relationships;
- enabling available and appropriate supportive resources;
- promoting a responsive Pilot Project; and
- ensuring cost-effective provision of attendant services.

The data collected to date indicate both achievements and ongoing challenges related to the realization of these desired outcomes.

### A. Consumer-driven partnership

The Pilot Project was originally envisioned by users of attendant services and their advocacy organizations as a way of demonstrating that self-managed attendant services would enable greater self-determination and socio-economic participation for persons with disabilities. From the early stages of this Pilot's development, there was a commitment to building a partnership to guide the Project's design and implementation. It was hoped that this partnership would bring together consumer organizations, government and individuals with disabilities who would work together in a collaborative fashion to shape a project based on the principles of the independent living movement. The evaluation points to a number of achievements and challenges in maintaining and strengthening this partnership.

#### Steering committee membership

The Steering Committee included representatives from:

- the Ministry of Health;
- the Ministry of Citizenship;
- the Ontario Network of Independent Living Resource Centres, including CILT as the Project Administration;
- the community of persons with a disability who use attendant services, including seniors; and

- the attendant worker labour pool.

Over half of the Steering Committee were and are people who use attendant services. Three self-managers funded under this Pilot Project sit on the Steering Committee. In interviews for the evaluation, two other self-managers indicated that they would like to be more involved in the Steering Committee, particularly if the Pilot Project is continued as a permanent program.

Under the Pilot, self-managers established employer-employee relationships with their attendants. However, some respondents to the attendant worker survey felt that more avenues are needed for attendants to raise their issues and concerns in order for them to be addressed. Approximately 20% of attendant workers who responded to the survey suggested room for improvement in their employment situation.

### **Development of strong partnerships**

All partners pointed to the strength of the partnerships created through the Pilot and to their effectiveness, which resulted in large part from the shared commitment of all partners to independent living principles and goals. Consequently, decision-making processes in the Steering Committee were managed in a consensual manner, with the processes respecting the goals and mandate of the Pilot Project. The Steering Committee meetings, held on a regular basis, provided a mechanism for ongoing consultation between government, the Centre for Independent Living in Toronto (CILT) as the Project Administration and community representatives. The positive relationships struck at the Steering Committee level provided for a collaborative approach to addressing issues and maintaining dialogue between meetings.

This partnership led to an administrative structure that provided an opportunity to consumer-controlled organizations to strengthen their capacity in program design and services in areas (i.e., self-management and direct funding) that they have long articulated as a goal.

Independent Living Resource Centre (ILRC) representatives who were interviewed affirmed the importance of involving consumer-controlled organizations in all aspects of the Pilot. They indicated that the regularly scheduled conference calls with ILRCs and other information support from CILT were helpful to ILRCs in learning about successes and challenges faced across the province. As one representative said, the collaboration fostered through this Project has laid the foundation for a continued and expanded direct funding initiative.

### **Consumer-controlled application and selection process**

As part of the independent living approach, the concept of self-assessment was piloted as an alternative to traditional professional assessment, and as a means of enabling greater consumer control or self-determination in the application process. Applicants themselves took on responsibility for and the lead role in creating and submitting their own individual proposals. They were asked to define their own service needs, create their own service plans and budgets and provide personal examples to demonstrate their capacity for self-management. The intent was to design an application process that was driven by individual consumers.

The selection process, designed in collaboration with government, also involved some very important innovations consistent with consumer-controlled Project design and implementation. At least two out of the three members on all nine regional selection panels used attendant services. It was consumers who validated the needs of prospective self-managers for attendant services, and also assessed the capabilities of applicants for self-management. Self-managers negotiated their individual proposals with the selection panellists. Several self-managers commented on the importance of attendant service users predominating on the selection panels. For example, one self-manager indicated, "The selection process, involving peer validation, was very important."

## **B. Participation in the Pilot Project**

Becoming a participant in the Project entailed a number of steps for applicants. The Project aimed to develop a fair application and selection process, ensuring that a representative mix of self-managers would be selected. Making the transition to self-management was an important shift for many individuals who participated. The process designed to enable individuals to make this shift resulted in a number of outcomes.

### **Information strategy**

Information about the Pilot Project was widely circulated prior to applications being made available. Participants learned about the Pilot from a variety of sources, including other users of attendant services, Ministry of Health Long-term Care Area Offices, the Ontario Human Rights Commission, service providers, Independent Living Resource Centres and other disability organizations (for example Canadian Paraplegic Association, Advocacy Resource Centre for the Handicapped), and the media (for example, the Disability Network and *Abilities* magazine). ILRCs took a number of steps to raise awareness of the Pilot Project in their areas, including presentations to service providers, interviews with journalists, mailing out information and notifying their memberships.

## Criteria for participation in the Pilot Project

As described above, participants in the Pilot Project had to meet three types of criteria laid out in the policy framework for the Project: 1) those related to types of services required; 2) those related to demographic characteristics (e.g., age and permanent physical disability); and 3) capacity and willingness to self-manage attendant services.

Almost all self-managers in the Pilot and representatives of ILRCs who participated in the research viewed the eligibility criteria as fair. However, three concerns were raised:

- requirement that participants either vacate SSLUs or demonstrate that their continued residence would not prevent another person from receiving attendant services

There appears to be some variation in how this requirement is interpreted by self-managers. Some self-managers interpreted this provision to mean that they had no choice but to move. For example, one respondent said, “[It’s] not fair to require people to move out of their home and community just to get on the program. There is a contradiction there.” Another indicated, “I had to fight to stay where I am. There aren’t many accessible units out there. I should be able to receive DF [Direct Funding] without it affecting where I am living.”

Others negotiated arrangements to enable another consumer to receive attendant services from an SSLU, and thereby remain in their apartment. Two participants who were selected in 1995 report that they continue to reside in a building with SSLUs, but that they no longer receive services and that someone else in the building is now receiving services that they were not before. Two participants selected in 1996 will remain in their apartments, but replacement units will be renovated in order to make them into SSLUs.

Two participants selected in 1996 maintained that services and housing should be de-linked, and another two reported difficulties in their efforts to locate alternative accessible housing.

- stability of disability

The requirement that the disability had to have been stable for at least the last year led a couple of self-managers to wonder if they would cease to be eligible should their condition progress, and others to fear that people who could definitely benefit from direct funding would not have an opportunity to participate.

- capacity to self-manage

An over-arching criterion for eligibility, selection and ongoing participation in the Pilot is that of self-management skills and capacity. Applicants were measured against this criterion in a number of ways, all of which emphasized individual capability. Concern was expressed by staff from three different ILRCs that this criterion could unfairly restrict access to direct funding by people with disabilities. It was suggested that self-direction, rather than self-management, be used as the basis for determining eligibility and selection. One ILRC representative stated:

*"I hope that this Project is expanded to include people who can [only] self-direct their services. Otherwise, it could get to the point that only people who are more schooled or more intelligent get direct funding. If people are labelled unable to receive direct funding after one interview, that's wrong. So many people with disabilities, such as people who reside in institutions, have not had opportunities to learn. Most can learn to 'self-direct' if they are given the opportunity. They can learn to express their preferences and needs, even if they may never be able to handle all the financial and administrative responsibilities independently."*

### **Application and selection process**

The application and selection process entailed completing an application form and undergoing an interview with a three-member selection panel. Aspects of the application and selection process reviewed in the research conducted for this evaluation include:

- preparing the application package

Respondents provided a number of comments in relation to preparing the application package. Typically, respondents felt the information asked for in the application package was clear and fair. The assistance that some received from ILRCs in filling out forms was appreciated. A few suggested that the forms could be simplified. Two respondents interpreted the suggestion that letters of reference be included with the application as a requirement, and felt that requesting letters of reference was inappropriate in accessing needed attendant

services. One of these respondents indicated that the "letters of support requirement made me feel as though my whole person was put in question."

- composition of selection panels

Self-managers generally indicated high levels of satisfaction with the composition of the selection panels, pointing to the importance of having peers participate on the panels, to the gender make up of the panels, and to the regional representation on the panels. The one critical comment was made by a representative of an ILRC, who indicated that because, in most cases, two out of three selection panel members were ILRC staff, this could lead to the perception that ILRCs were acting as gatekeepers in selecting participants for the Pilot. The concern was expressed that this may compromise the ILRCs' mandate to act as a resource to all people with disabilities in the community. Other representatives of ILRCs did not believe this was cause for concern.

- the selection process

The selection process was perceived by almost all self-managers selected in 1995 as comfortable and fair. A smaller proportion of those selected in 1996 perceived the process as such. Five of twenty-four (21%) felt the process was uncomfortable, and seven (29%) felt the process was unfair.

All respondents indicated that they appreciated the personal interviews. Respondents stated the interviews provided an opportunity to learn more about how to manage attendant services effectively, what would be the most appropriate schedule for attendants given their needs, and what services an attendant could provide under the Project. Most considered that the interviews were conducted in a professional manner, providing for in-depth questions, and careful consideration of individual situations. As one respondent stated, "I was anxious about the interview, but the panel put me at ease."

Those who felt the process was unfair pointed to a few concerns. A few respondents wondered what the priorities were in selecting participants. In particular, they felt that the degree of unmet need for attendant services should be taken into account to a greater extent. It was also felt by a few self-managers that the interview focussed unduly on the applicant providing justification for the proposed budget as a basis for selection. A few respondents also felt that the atmosphere at the interview was not comfortable. Four respondents indicated they felt put on the defensive about their budget and their needs, and stated they felt either anxious or intimidated as a result. Another indicated that it felt like a

"job interview" and that this was inappropriate for an interview determining access to services. A couple of ILRC representatives suggested that in scoring self-management capacity, there was a need for flexibility in interpreting the scores in order to minimize exclusion from the benefits of direct funding, and to maximize representativeness of those selected.

In many cases, applicants' plans for managing attendant services were refined during the course of the selection panel interview. The number of hours requested and the allocation of these hours frequently underwent changes as the panel discussed the requirements of each individual. Only thirty of the seventy-eight applicants selected in 1995 were recommended for the same number of hours as originally requested on the application forms. In most cases, fewer hours were recommended than originally requested.

### **Profile of non-selected applicants**

The forty-four applicants who were interviewed in 1995, but who were not selected as participants in the Pilot Project, represented a diverse group. Twelve were not accepted because they did not meet the eligibility criteria. Twenty-one of them were men and twenty-three were women. Twelve identified themselves as rural residents, with the remaining thirty-two identifying themselves as urban dwellers. Ten were younger than thirty and three were older than sixty-five; the mean age was forty-two and the median age was forty-three. All six regions were represented among this group. (See Appendix #4 for a map of Ontario indicating the boundaries of the six regions.)

Fourteen individuals were interviewed in 1996 but were not selected; two of them because they did not meet the eligibility criteria and twelve on other grounds. Five were women and nine were men. Two identified themselves as rural residents and the other twelve identified themselves as urban residents. The oldest non-selected individual was sixty-five and the youngest was twenty-five. All regions, except for the North East, were represented in this group.

Of the fifty-eight non-selected applicants, slightly more were men (30, 52%) than women (28, 48%), and, as Figure 1 shows, over 40% resided in the Central East region. Given that this region is the most urbanized in the province, it is not surprising that a greater proportion of the non-selected applicants reside in an urban area (44, 76%) than in a rural area (14, 24%).

Figure 1. Non-Selected Applicants' Region of Residence

	Not selected in 1995		Not selected in 1996		All non-selected applicants	
	Frequency	%	Frequency	%	Frequency	%
Central West	7	16	1	7	8	14
Central East	16	36	9	64	25	43
East	8	18	1	7	9	16
North East	5	11	0	0	5	9
North West	3	7	1	7	4	7
South West	5	11	2	14	7	12
Total	44	100	14	100	58	100

These non-selected applicants' scores on the self-management skills measure also varied considerably. The four highest scores were assigned to individuals who could not be funded because their private insurance benefits were judged to be sufficient to meet their attendant service needs for at least one more year.

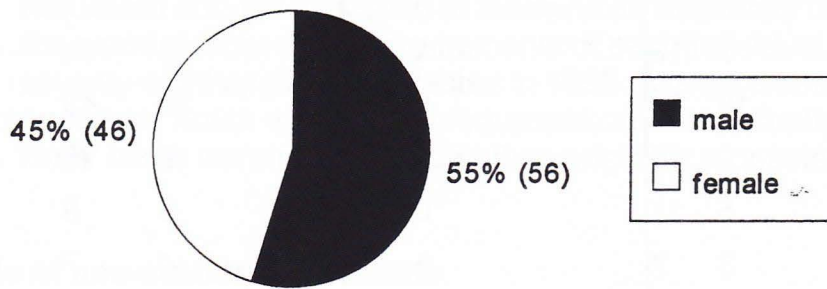
### Profile of selected applicants

One of the aims of the Pilot was to ensure that a diverse group of participants would be selected. By and large this aim has been achieved.

#### *Demographic characteristics*

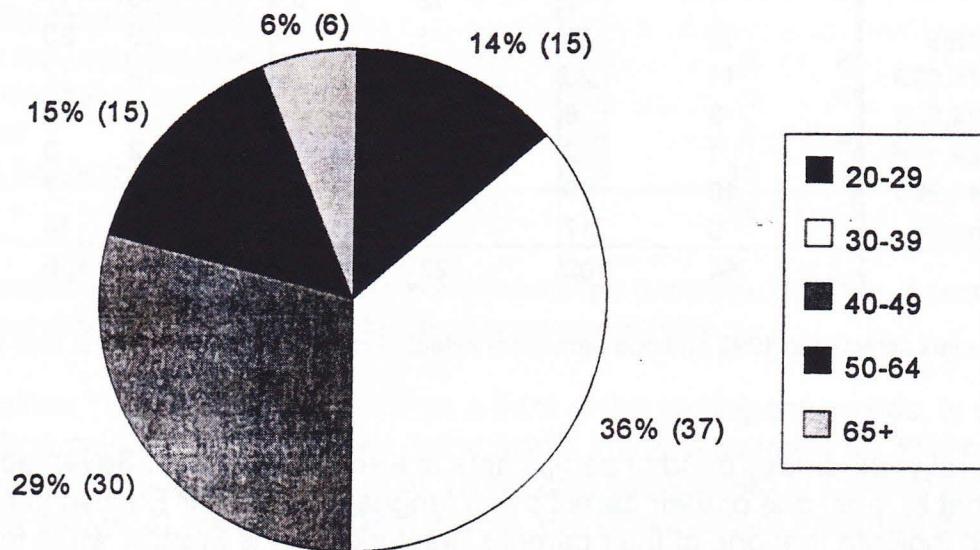
Of the 102 participants selected as participants for the Pilot, fifty-six are men and forty-six are women. Statistics Canada data indicate that approximately 48% of the people who appear to meet the eligibility criteria for the Pilot are men, and that approximately 53% are women.

Figure 2. Gender of Selected Applicants



The age of participants ranges from twenty to seventy-three, with 65% of participants in the 30-49 age range. The mean age is 40.

Figure 3. Age of Selected Applicants



Participants' income varies considerably. Nineteen reported incomes under \$10,000 at the outset of the Pilot, while eleven reported income over \$ 45,000 in the year prior to their selection.

As a group, people with disabilities are disproportionately poor (Bach and Rioux 1996; Rioux and Crawford 1990). According to Statistics Canada data, the same proportion of residents of Ontario who would appear to meet the eligibility criteria for this Pilot reported incomes of less than \$10,000 in 1991 (45%). A greater proportion of participants have incomes of \$30,000 or more (30%) than other Ontarians who appear to meet the eligibility criteria (15%).

Figure 4. Selected Applicants' Pre-Pilot Income Levels

	Selected in 1995 (total income in 1994)		Selected in 1996 (total income in 1995)		All respondents		
	Frequency	%	Frequency	%	Frequency	%	Cum %
\$0	1	2	1	4	2	3	3
\$1- \$4,999	1	2	12	52	13	17	20
\$5,000 - \$9,999	18	33	1	4	19	25	45
\$10,000 - \$14,999	11	20	2	9	13	17	62
\$15,000 - \$24,999	3	6	1	4	4	5	67
\$25,000 - \$29,999	1	2	1	4	2	3	70
\$30,000 - \$44,999	10	19	3	13	13	17	87
\$45,000 or more	9	17	2	9	11	14	100
Total	54	100	23	100	77	100	

• Four participants selected in 1995 and one participant selected in 1996 declined to share their pre-Pilot incomes.

Ethno-culturally, the background of participants is also quite diverse. Seventeen indicated that at least one of their parent's first language is neither English nor French and thirteen indicate that one of their parent's first language is French, while four identified themselves as visible minorities. None of the respondents identified himself or herself as aboriginal.<sup>2</sup>

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<sup>2</sup> Steering Committee representatives did meet with the committee on long-term care of the Chiefs of Ontario in 1995 in order to share information about the Pilot Project.

Figure 5. Selected Applicants' Ethno-cultural Background

	Selected in 1995		Selected in 1996		All Respondents		
	Frequency	%	Frequency	%	Frequency	%	Cum %
parent's first language neither English nor French	10	17	5	21	15	18	18
parent's first language French	9	16	2	8	11	13	31
visible minority	3	5	1	4	4	5	36
aboriginal	0	0	0	0	0	0	36
parent's first language English	41	71	18	75	59	72	108
N	58		24		82		

• These variables were part of a question that allowed multiple responses. Therefore, the sums of the frequencies exceed N and the sums of the percentages exceed 100%.

Metropolitan Toronto, where more than a third of the participants reside, is one of the most ethno-culturally diverse cities in the world. Immigrants make up 38% of Toronto's total population, and about 40% of all immigrants who arrived in Canada between 1981 and 1991 settled in Toronto (Badet 1993, p. 10). About 35% of Toronto's population does not speak English or French as a first language (Metropolitan District Health Council Working Group on Services for People with Physical Disabilities 1996, p. 35). In 1991, 24% of all adult visible minorities in Canada resided in Toronto (Kelly 1995, p. 4).<sup>3</sup>

People with disabilities are less likely than people without disabilities to be accepted as immigrants to Canada (Canada 1992; Canadian Association for Community Living 1992). This policy is reflected in Statistics Canada data. Immigrants are less likely than people born in Canada to report a long-term disability or health condition<sup>4</sup>: 50% versus 57%. As the length of time in Canada increases, so does the reporting of long-term

<sup>3</sup> In the 1996 census, Statistics Canada asked for the first time whether respondents identified themselves as a visible minority. The data from the 1996 census is not yet available. Therefore, it is difficult to accurately determine the number of visible minorities with and without disabilities in Canada. Statistics Canada, on the basis of ethnic origin data, place of birth data, and mother tongue data, estimate that 1.9 million adults residing in Canada in 1991 were visible minorities and that two-thirds of all visible minorities have come to Canada as immigrants or refugees since 1972. Most visible minorities have settled in urban areas.

<sup>4</sup> A long-term health condition could include asthma or heart disease.

disabilities or health conditions. Only 35% of those who have lived in Canada for fewer than six years report long-term disabilities or health conditions, whereas 48% of those who have lived in Canada for between six and ten years and 55% of those who lived in Canada for more than ten years report long-term disabilities or health conditions (Statistics Canada 1995, p. 16).

Difficulties also exist in accurately determining the number of aboriginal people with disabilities in Canada. However, the incidence of disability among aboriginal peoples is two to four times the national average, with two-thirds of these relating to mobility and agility (Halliday 1993, p. 19). It appears that approximately one-third of all aboriginal people in Ontario have at least one disability (Platiel 1994).

As a group, the participants have relatively high levels of education. Fifty-seven report at least some post-secondary education; seventeen report that they have completed a university degree; sixty-one report that they have completed high school. A greater proportion of selected applicants (57%) report at least some post-secondary education than other residents of Ontario who appear to meet the eligibility criteria (20%).

Figure 6. Education Levels of Selected Applicants

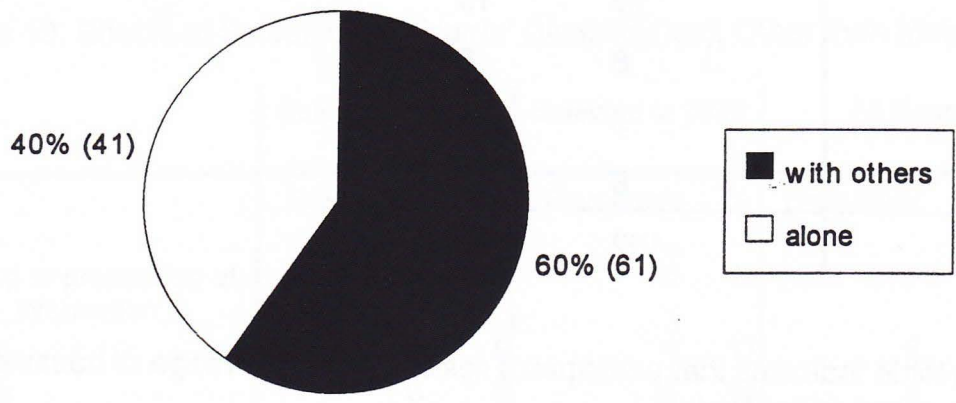
	Selected in 1995		Selected in 1996		All Respondents		
	Frequency	%	Frequency	%	Frequency	%	Cum %
completed high school	39	67	22	92	61	74	74
begun post-secondary program	10	17	3	13	13	16	90
completed certificate or diploma	19	33	9	38	28	34	124
completed university degree	12	21	5	21	17	21	145
N	58		24		82		

• These variables were part of a question that allowed multiple responses. Therefore, the sums of the frequencies exceed N and the sums of the percentages exceed 100%.

### *Living situation*

At the outset of the Project, twenty participants reported living in a rural area, and eighty-two identified themselves as urban residents. Forty-one lived alone and sixty-one reported living with one or more persons.

Figure 7. Selected Applicants' Pre-Pilot Household Composition



Given that this Pilot was designed as a province-wide initiative, efforts were made to ensure a representation of participants from all regions of Ontario. The following table illustrates the distribution of participants across provincial regions. (Appendix #4 contains a map of Ontario indicating the boundaries of the six regions.)

Figure 8. Selected Applicants' Region of Residence

	Frequency	%
Central East	52	51
Central West	10	10
East	19	19
North East	8	8
North West	5	5
South West	8	8
Total	102	100

The following table indicates that participants resided in a wide range of housing options at the outset of the Project.

Figure 9. Selected Applicants' Housing Tenure Pre-Pilot

	Selected in 1995		Selected in 1996		All respondents	
	Frequency	%	Frequency	%	Frequency	%
rent apt (privately owned)	10	18	2	8	12	15
rent house	1	2	1	4	2	2
rent public housing unit	5	4	2	9	7	9
rent apt in SSLU building	9	18	7	29	16	20
cooperative	3	5	2	8	5	6
privately owned house or condo	27	48	6	25	33	40
family-owned dwelling	3	5	4	17	7	9
Total	58	100	24	100	82	100

### *Disability and disability-related supports*

Some selected applicants indicated that their disabilities not only affected their mobility or agility. Seven indicated that their vision is also affected; nine indicated that their speech is also affected; three reported that their learning and processing of information is affected; and eleven indicated that their mental health is also affected by their disability.

Figure 10. Effects of Selected Applicants' Disability(ies), Other than Mobility and Agility

	Selected in 1995		Selected in 1996		All Respondents		
	Frequency	%	Frequency	%	Frequency	%	Cum %
learning or processing of information	0	0	3	13	3	4	4
speech	5	9	4	17	9	11	15
hearing	0	0	3	13	3	4	18
vision	3	5	4	17	7	9	27
mental health	3	5	8	33	11	13	40
N	58		24		82		

• These variables were part of a question that allowed multiple responses. Therefore, the sums of the frequencies exceed N and the sums of the percentages exceed 100%.

A total of sixty-two selected applicants reported that they acquired the disability resulting in their need for attendant services after birth, at a mean age of twenty-two. Statistics Canada data indicate that, of those residents of Ontario who appear to meet the eligibility criteria, the condition limiting their mobility and agility was present at birth in approximately the same proportion (22%) as among the Pilot participants (24%).

Figure 11. Onset of Disability(ies) Resulting in the Need for Attendant Services

	Selected in 1995		Selected in 1996		All Respondents	
	Frequency	%	Frequency	%	Frequency	%
present at birth	12	21	8	33	20	24
acquired	46	79	16	67	62	76
Total	58	100	24	100	82	100

Participants selected in 1995 were asked about their requirements and use of disability-related devices. Without exception, they reported requiring and using a wheelchair. Some individuals used both a manual and electric wheelchair. Three-quarters indicated that they used a computer, in some cases with adapted software. Almost all of those who did not have a computer indicated that they would like to obtain one. All reported requiring at least some environmental modifications, such as ramps or easy-to-open doors. Most had access to the modifications that they require at home, though one individual noted that he had not seen the basement of his home for several years, since acquiring his disability. However, most reported that at least some of the environmental modifications that they require were often lacking in their workplaces and/or in public facilities. Accessible transportation was of particular concern.

#### *Pre-Pilot attendant service arrangements*

Prior to their selection for the Pilot Project, most participants had some paid hours of attendant service. However, nine relied entirely upon unpaid support from family and friends. Forty-five reported on their application form that they relied on family and friends for at least some assistance, fifteen of whom typically received 150 hours or more per month. Of those with access to at least some paid services, the total number of combined paid service hours, including private hiring, received prior to the Pilot Project ranged from fewer than fifty hours per month to over two hundred.

Figure 12. Number of Unpaid Hours Provided Per Month by Family Members Pre-Pilot

Hours	Frequency	%	Cum. %
0	57	56	56
1-59	18	18	74
60-89	3	3	76
90-119	6	6	82
120-149	7	7	89
150-179	4	4	93
180-209	3	3	96
210-435	4	4	100
Total	102	100	

It appears that most self-managers continued to receive at least some unpaid assistance from family and friends while participating in the Pilot Project. Forty respondents (63%) to the follow-up survey of participants selected in 1995 reported that family and friends regularly provide unpaid attendant services. Typically, these respondents receive fewer than fifty hours per month (twenty-seven respondents, 43%). However, four respondents (6%) reported that, on average, they continue to receive more than 150 unpaid hours of service per month.

Figure 13. Number of Sources for Paid Attendant Services Pre-Pilot

	Frequency	%	Cum. %
0	9	9	9
1	42	41	50
2	45	44	94
3	5	5	99
4	1	1	100
Total	102	100	

As shown in the figure above, of those who received at least some paid attendant services, most relied on two or more sources. The following figure indicates that a range of sources were drawn upon.

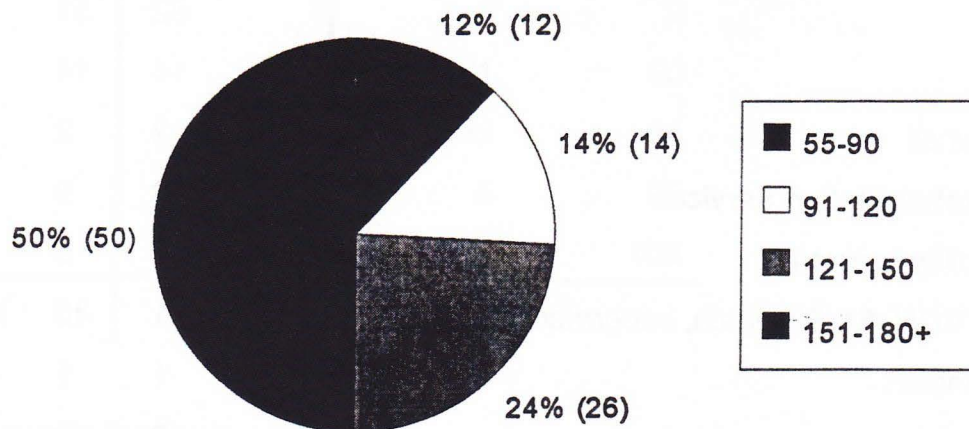
Figure 14. Paid Service Arrangements Pre-Pilot

	Frequency	%
Outreach	52	51
SSLU	14	14
Order-in-Council	2	2
Vocational Rehabilitation Services	9	9
Private disability insurance	5	5
Home Care, VON, St. Elizabeth, Integrated Homemaker	41	40
Veteran's pension	1	1
Municipal social services	2	2
out-of-pocket hiring	12	12
hospital or hospice	2	2
community service agency	2	2
services paid for by employer	3	3
N	102	

• Frequency and percentage totals exceed 102 and 100, respectively, even though nine individuals did not receive formal paid services prior to the Pilot

Participants' intensity of need for attendant services varies considerably. Fifty require more than 150 hours per month. Twelve require ninety or fewer hours per month. The lowest number of hours per month approved under the Pilot was fifty-five. Twenty individuals were approved for 180 hours. The mean number of approved hours was 142 and the median was 147.

Figure 15. Number of Hours Per Month Approved by the Steering Committee



### *Self-management skills*

Those selected had high scores on the measure developed by CILT to standardize assessment of self-management skills.

A third of those selected in 1995 were assigned the maximum score, twenty-seven. Eight received a score of twenty or less. The lowest score of an accepted applicant was thirteen. This individual, in her early twenties, was judged to have good potential, though she had limited experience. The next lowest score, eighteen, was assigned to an individual from a remote region; this individual was selected, in part, to enhance the demographic mix.

Prior to the interviews in 1996, the standardized measure of self-management skills was revised to incorporate individuals' self-management potential in addition to their experience. Communication, presentation and negotiation skills were scored<sup>5</sup>, as were the individuals' comfort with making decisions and taking reasonable risks. The maximum score on the revised measure was forty-five. Of the twenty-two selected

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<sup>5</sup> Verbal communication and presentation skills were not assessed. Some of the participants have a disability that affects their speech. One of the participants selected in 1996 is non-verbal.

applicants scored on the revised measure, twelve were assigned a score of forty-four or better. The mean and median scores were thirty-seven.

### Satisfaction with participation

On the whole, self-managers are pleased with the Pilot. Fifty-six of respondents selected in 1995 (89%) indicated that they are very satisfied with their participation in the Pilot. Eighteen of the twenty-one participants selected in 1996 (86%) who have begun spending their funds report that they are very satisfied. All other respondents indicated that they are generally satisfied.

Figure 16. Self-Managers' Satisfaction with the Pilot Project

	Selected in 1995		Selected in 1996		All respondents	
	Frequency	%	Frequency	%	Frequency	%
very satisfied	56	89	18	86	74	88
generally satisfied	7	11	3	14	10	12
Total	63	100	21	100	84	100

• The three self-managers selected in 1996 who will begin spending their funds in January 1997 have been excluded from this table.

All respondents to the surveys of self-managers report that they would recommend self-managed direct funding for attendant services to others.

### C. Flexibility, choice and control over attendant services

The Pilot was designed with independent living goals in mind and, in particular, with the goal of facilitating flexibility, choice and control over attendant services as a means of enabling people with disabilities to live fuller, more active lives. The data point to an impressive list of achievements of the Pilot in this regard, and to some ongoing challenges. Most participants seem to have experienced significant improvements in this area directly after the transition to self-management, and some continue to report improvements even many months after their participation began. Moreover, participants found that any drawbacks of self-managed direct funding were substantially less than anticipated.

## Direct funding for attendant services

The primary mechanism for enabling greater choice in and control over attendant services in this Project is the provision of funding directly to individuals so that they can hire, direct and manage their own attendants.

Funding conditions were clear to most participants, although it was not initially clear if those with private insurance benefits would be eligible and, if so, under what circumstances. The contract between CILT and self-managers was understood by almost all respondents, although a few indicated unspecified areas in the contract that they were not sure they understood fully.

Project Administration records indicate that half of the self-managers selected in 1995 are running a surplus. Fourteen self-managers selected in 1995 (22%) indicated in the follow-up survey of that they need fewer hours than originally approved, and thirteen respondents (21%) stated that they require more hours. Of those indicating that they require more hours, five had been allotted the maximum number of hours under the Pilot. Those who require additional hours may obtain approval from the Pilot Administration to access their personal contingency fund (10% of their annual budget for those selected in 1995, reduced to 5% for those selected in 1996 based on administrative experience gained in 1995). As of November 1996, eleven self-managers had requested access to their contingency fund, of whom nine were approved.

Five concerns about funding policies for the Pilot were identified in the research:

- employee benefits

Some respondents indicated a lack of clarity about the policy on providing travel allowances for attendants, and felt that the limitations on the claims contributed to difficulties in recruiting and retaining attendants (e.g., disallowance of mileage claims, one-way transit fare rather than return fare). A few respondents also felt funding should be provided for health benefits, in order to provide a benefits package comparable with that provided by many agencies.

- maximum wage levels

While the wage thresholds for the Pilot Project were consistent with provincial averages, a few respondents from the Greater Toronto Area felt the maximum wage levels were too low to attract quality staff, given that higher scales are paid to attendants in some agencies.

- cap on hours

It was suggested by some self-managers and ILRC representatives that the maximum of 180 hours per month is too low to accommodate the needs of all those who meet the eligibility criteria.

- accountability for funds

A few respondents reported that the accountability requirements seemed too onerous and suggested bi-annual rather than quarterly reporting. One respondent stated that no two dates coincided for reporting to the Pilot and to government, and suggested that it would be easier if at least some of these reporting dates coincided (e.g., quarterly report, receiver general, payroll periods).

- security of funding for self-managers on the Pilot Project

Concern was expressed about the security of direct funding arrangements, given the positive impact it has had on so many people's lives. One respondent stated,

*"I'm very concerned that the Pilot will end. It would be like going back in time. Prior to DF [direct funding] I thought about ending my life. After about three months on the Pilot, I no longer had these thoughts."*

Another indicated that he would only feel comfortable making longer-term plans in his life when he was secure that funding would continue beyond the Pilot phase.

### **Transition to self-management**

While most self-managers made a speedy transition to self-managing with direct funding, a few encountered challenges including:

- locating accessible housing;
- obtaining insurance;
- recruiting attendants for particular shifts;
- recruiting attendants willing to work for maximum wages set by Project;
- the stress of taking on management responsibilities; and
- making book-keeping arrangements.

In interviews, most self-managers indicated that prior managerial and other professional work experience enabled them to make a smooth transition to self-managed direct funding. Those without management experience, one self-manager maintained, would be at a disadvantage. Those with little management experience commented that the transition period was somewhat difficult, and a few indicated that it was overwhelming.

### **Choice and control in attendant services**

The Pilot Project has enabled self-managers to choose their own attendants. More than two-thirds of respondents have hired a former attendant, suggesting that the benefits enjoyed are not a function of new personnel in many cases, but rather the nature of the relationship between the self-manager and the attendant put in place through this initiative. Many, however, wanted to change their attendants, and did so by recruiting and hiring new workers. (For more detail, see section on employer-employee relationships).

The choice in and control over attendant services exercised by self-managers enabled them to reprimand attendants, or replace those whose performance proved to be unsatisfactory. Self-managers identified various reasons for reprimanding and dismissing attendants, including:

- abusive behaviour;
- stealing;
- disclosing confidential information;
- unreliability;
- lack of respect for the self-manager's beliefs; and
- reluctance to accept direction from the self-manager.

Along with increased choice in attendant services, most reported increased choice in their lives overall. None of the respondents indicated that their ability to make choices in attendant services or in their lives as a whole had decreased. More than two-thirds of respondents also reported that their control over attendant services and in their lives overall had improved. No one indicated that their control had diminished.

Figure 17. Choice and Control in Attendant Services and Overall

	Selected in 1995				Selected in 1996		All respondents when initially surveyed	
	First Survey		Follow-up Survey		Frequency	%	Frequency	%
increased choice in attendant services	52	90	22	35	17	81	69	87
increased choice overall	48	83	39	35	19	90	67	85
increased control over attendant services	51	88	29	35	20	95	71	90
increased control overall	50	86	34	35	21	100	71	90
N	58		63		21		79	

• Three self-managers selected in 1996 reported that they intend to begin spending funds allocated to them in January 1997, and so have been excluded from this table.

Respondents testified in a number of ways to the importance of increased control over attendant services, and compared the control they have now to previous service arrangements. Statements from four respondents are illustrative:

*"In my previous living arrangement, before DF [direct funding], attendants told me what they would and wouldn't do. I had no control."*

*"The [other] program does not screen the attendants and the fact that you have different people helping with such personal needs is degrading morally and physically. When you are in control of meeting your own needs, it is the next best thing to doing it yourself. One does not dread the next day's shower and other necessities as much. My attendant knows what help I need and I do not have to explain the procedure each day."*

*"Before . . . my privacy was constantly invaded by disgruntled, vengeful, intimidating workers - these were the people with whom I had to spend the first hours of my days and the last hours at night. Now I have people who care, who are responsible and who I can trust. This is a great enrichment to my life."*

*"My flexibility has increased 100% since becoming a self-manager. The project where I used to live had set times and if you missed those times, you might have to wait a few hours until the attendant was able to help you. If I want to bake right away or do cleaning, I can do that. Handling cooking and other household duties has improved 100%. I feel so complete and relaxed now even though there is a lot of organizing with this Project."*

Two concerns were raised with respect to choice and control over attendant services:

- the "family clause"

Some respondents did indicate dissatisfaction with the policy prohibiting family members from being hired, even in emergency situations. Respondents, including both self-managers and attendants, suggested that family members could be paid for back-up services when the scheduled attendant could not work, and for emergency services. Furthermore, it was suggested that the restriction on hiring family members could inadvertently limit the participation of aboriginal people living in communities in which many residents are immediate family.

- interruptions in service availability

Even with increased control for many participants, a few have reported interruptions in service arrangements. Twelve individuals selected in 1995 (19%) reported in their follow-up survey that they had experienced an interruption since January 1996. Various reasons for interruption in service arrangements occurred, with most lasting a few hours. Some of the reasons included last minute cancellations, illness of workers, and turnover of staff.

## Flexibility, choice and control as foundation for improved quality of life

Self-managers pointed to a number of ways in which the increased flexibility, choice and control in attendant services has affected their quality of life. These additional benefits are reflected in the following table.

Figure 18. Benefits Associated with Choice, Flexibility and Control

Areas of improvement	Selected in 1995		Selected in 1996		All respondents when initially surveyed			
	First Survey	Follow-up Survey						
	Frequency	%	Frequency	%	Frequency	%		
management skills	47	81	38	60	20	95	67	85
independence	50	86	37	59	20	95	70	89
personal comfort	48	83	41	65	16	76	64	81
social, leisure activities	48	83	31	49	11	52	59	75
relationships with family, friends	37	64	20	32	9	43	46	58
relationship with an intimate partner	28	48	15	24	8	38	36	46
participation in education	13	22	10	16	3	14	16	20
employment opportunities	18	31	17	27	5	24	23	29
ability to travel	40	69	27	43	14	67	54	68
N	58		63		21		79	

• Three self-managers selected in 1996 reported that they intend to begin spending funds allocated to them in January 1997, and so have been excluded from this table.

The qualitative data from surveys and interviews corroborate these quantitative findings:

- increased independence

Many respondents indicated that self-managing their attendant services brought greater independence, allowing them to make desired changes in their lives. As one self-manager said,

*“During my 33 years of living with a disability, I have strived to obtain independence. In the last two years, this Pilot Project has allowed me to achieve this independence. It has given me an opportunity to choose a lifestyle that is appropriate for me.”*

For some self-managers, greater independence meant being able to live out of their parents’ home, or meant they did not have to return to living there.

For some self-managers, along with increased independence has come increased opportunity for both business and personal travel. One stated,

*“It may sound like a small thing, but for the first time in fifteen years, I took a vacation. My attendant came with me, and we had a great time. I was able to see family who live in the area. It’s something that would never have been possible without direct funding.”*

A few self-managers indicated the opportunity to travel was making a positive difference in the careers and business opportunities.

- improved security

Some self-managers found that with greater control and choice in attendant services their sense of personal and financial security in their lives also increased. (For further discussion of increased financial security, see section on social and economic participation). Self-managers indicated that their sense of vulnerability, stress and worry had diminished greatly. Three self-managers said they could contemplate having children now that they had greater control in their lives. Another stated,

*"I don't worry the way I used to if my wife [who used to do all the attendant work] gets sick. I had worried that if she got sick, I would have to go to an institution. I have a better sense of security now."*

- self-esteem, personal relationships and fulfilment

Increased choice, flexibility, and control in attendant services resulting from participation in this Pilot Project have had a significant positive impact on the self-esteem, personal relationships and sense of personal fulfilment of many participants. One self-manager commented that handling the administrative responsibilities entailed in self-management under this Pilot has enhanced self-esteem. Self-esteem has also been enhanced through reduced dependency on family and friends for assistance, as illustrated in the four statements below, including one from an attendant worker:

*"This program has helped me to gain my self-esteem, as I know that I can depend on the person of my choice to assist me in such intimate things as bathing or using the bathroom. I do not have the financial means to pay for the same . . . I can get out each day for shopping, exercise or appointments. I do not have to plead to my family for help to the bathroom, etc. It is very degrading and humiliating and extremely stressful to beg for help."*

*"In my experience, one of the most difficult things about having a significant physical disability is asking for favours. Having funds available to pay for work done has lessened my sense of vulnerability and burden."*

*"It's like I don't have disabilities anymore. I found my will to live dwindling prior to self-management. I was having more bad days than good."*

*"I have known my employer for many years. I have seen how her life was while she had to deal with the agencies that provided her care. She is much more relaxed now and also more fulfilled, since we can go out whenever and wherever she wishes to go."*

Self-managers also indicated that, in part because of decreased dependency, their relationships with family and friends have improved. Some of the self-managers expressed the improvement in their relationships with others in the following ways:

*"My husband is freer now to do things. He feels closer to me now."*

*"It is difficult to tell family members how to help you. But when you have a paid attendant, you are able to deal with them in a more business-like basis. They cannot complain about the work. Having an attendant has taken away any conflicts I had with family members about my personal care. They used to have to structure their lives around me, but that is not necessary any more."*

*"A once-in-a life-time benefit — I got married! I don't see how it would have been possible in the SSLU."*

*"I can join my friends as an equal now."*

- improved health and well-being

A number of self-managers reported improvements in their overall health and well-being. One individual who was interviewed for this evaluation said that she was "literally dying in the SSLU." She has not been in the hospital since being in the Pilot, whereas prior to the Pilot, she was admitted every four to six months. Another self-manager reported fewer migraines and better sleep due to relief of the stress of always having to accommodate other people's schedules. A couple of self-managers indicated that their skin health and personal hygiene has improved due to better attendant services. Two other self-managers indicated that long neglected appointments were made possible by the Pilot because an attendant could accompany them to the appointment. The difference between relying on institutional and self-managed services was summed up by one self-manager, who reported,

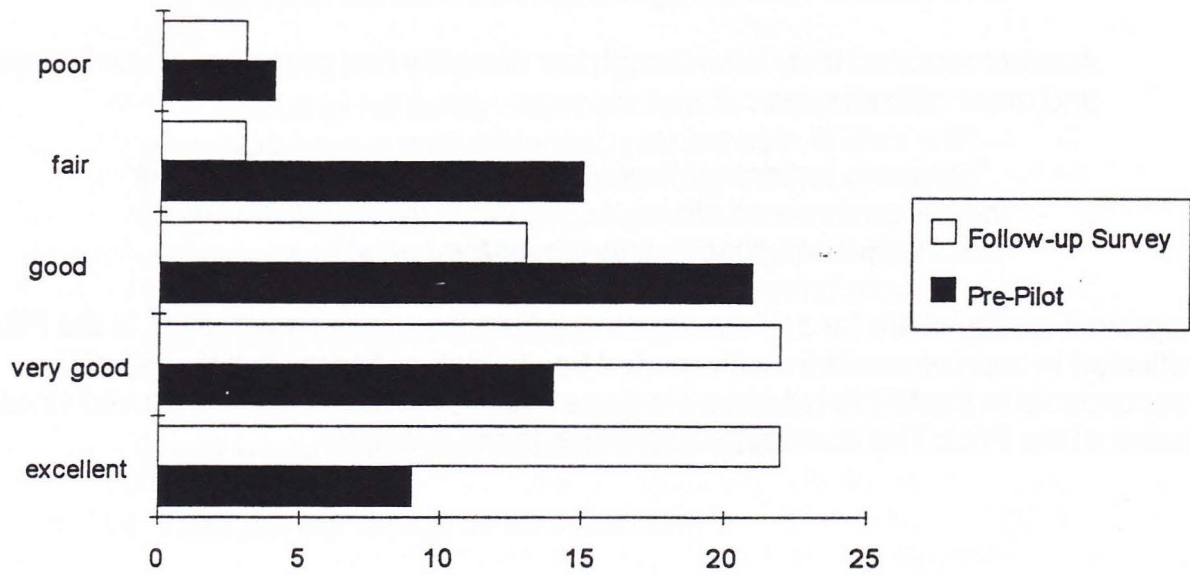
*"I much prefer self-management to that of a chronic long-term care hospital facility, which I experienced for a few weeks in 1995 and 1996. The latter was characterized by dependency on others, waiting for nursing care, no control and no decision-making by me. I was a passive recipient in all aspects rather than an active decision-maker in my care."*

Another reported that, even though her disability has progressed, she is happier and more relaxed now:

*"I have no restrictions, my stress has been reduced, there is no dependence on others. I cannot put into words how much this Project has changed my life for the better."*

Improved quality of life for self-managers resulting from their participation in the Pilot is reflected in improvements in self-reported health status. Approximately half of the respondents to the follow-up survey indicate that their overall health improved since the outset of the Pilot. The chart below illustrates these changes.

Figure 19. Changes in the Self-Reported Health Status of Participants Selected in 1995



- Prob. = 0.000
- Gamma: 0.593, Tau-b: 0.459, Tau-c: 0.421
- N=63

## D. Social and economic participation

In addition to Pilot Project goals to enable greater choice, flexibility and control in attendant services, increased social and economic participation were also desired outcomes. The research points to some significant achievements and some persisting challenges in this regard.

### Social and leisure activities

A number of self-managers made favourable comments regarding the impact of the Pilot in this area, including:

*"I could take swimming lessons with my daughter, which wouldn't have been possible with an agency-managed service."*

*"My opportunities for recreation and going out have improved."*

Two self-managers interviewed for the evaluation said that friends come to visit more often. One said that prior to the Pilot Project, visitors were made to feel uncomfortable because the staff refused to do any cooking or dishes for them, and made the visitors aware of this. Another said that the schedule would not accommodate plans to have friends over, and so visitors would feel that they had to leave when the attendant arrived.

Respondents to the first survey of self-managers selected in 1995 indicated statistically significant increases<sup>6</sup> in the frequency of social and leisure activities, in particular those outside the home, including:

- visiting informally with others;
- attending courses, seminars or conferences;
- going to community facilities and events;
- attending religious services and related activities; and
- shopping.

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<sup>6</sup> p=0.000 on gamma and Kendall's tau

## **Educational activities and participation in the labour force**

Ten self-managers selected in 1995 who are currently working part-time or full-time attribute this fact directly to the Pilot. One of these individuals commented,

*"DF [direct funding] enabled me to take a full-time permanent position, because I knew that my attendant service requirements would be met."*

Three said that they were now able to go on business trips, which they could not do before. Three more self-managers said that their performance has improved or that the number of hours they can spend working has increased. Two others, who are not currently employed, felt that their employability had been enhanced through the experience that they had gained as a result of the Pilot.

The employment status of participants is summarized in the next table. In addition, fourteen respondents to the follow-up survey of self-managers selected in 1995 (23%) and seven participants selected in 1996 (29%) reported planning to begin an educational program within six months.

Figure 20. Employment and Educational Status of Self-Managers

	Selected in 1995 Follow-up Survey		Selected in 1996		All respondents	
	Frequency	%	Frequency	%	Frequency	%
full-time job or FTE	19	30	7	29	26	32
part-time job	5	9	1	5	6	7
partly or mostly self-employed	12	19	1	4	13	16
looking for work	16	28	6	29	22	27
enrolled in a post-secondary program	9	14	3	13	12	15
volunteer 30+ hrs/wk	3	5	2	10	5	6
volunteer >30 hrs/wk	22	35	14	58	36	44
N	58		63		24	

• Percentage and frequency total exceed 100% and N respectively, as these questions were asked as multiple-response questions.

Respondents selected in 1995 also reported earning more from employment in 1995 than in 1994<sup>7</sup> as a result of the increased opportunities made possible through the Pilot. Eight (14%) reported earnings of \$45,000 or more in 1995, whereas five (9%) reported earning of \$45,000 or more in 1994, the year before the Pilot began. Twenty-nine of the respondents to the follow-up survey (51%) and fifteen participants selected in 1996 (63%) reported no earnings in 1995<sup>8</sup>.

<sup>7</sup> p=0.000 on gamma and Kendall's tau

<sup>8</sup> Six respondents to the follow-up survey and four respondents to first survey of self-managers selected in 1995 declined to disclose their earnings.

Statistics Canada data indicate that 69% of all Ontario residents who appear to meet the eligibility criteria for this Pilot reported no earnings in 1991. Only 5% of this group reported earning \$35,000 or more in 1991, and only 1% were enrolled in a college or university program.

The Pilot Project also has improved the employment situation for some self-managers' intimate partners. While the surveys did not ask about the income or employment status of other members of the household, three individuals indicated that their spouse has been able to enter the labour force as a result of the Pilot Project, and another's spouse can now work evening and night shifts.

### **Obstacles to social and economic participation**

Despite the high levels of social and economic participation reported by participants, they continue to face a number of obstacles. The fact that facilities, equipment or programs are not accessible to them ranked as the most common obstacle encountered by respondents to the follow-up survey of self-managers selected in 1995 (38 respondents, 63%). The next most common obstacle reported by this group was unmet needs for assistance from others (34 respondents, 57%). The third most common obstacle reported was high cost (35 respondents, 58%). Other reported obstacles included lack of nearby facilities or programs; needs for specialized aids or devices and inadequate transportation. Only ten respondents (17%) identified lack of support from family or friends as an obstacle. In interviews and in survey respondents' comments, inclement weather was identified as another obstacle. Two individuals with progressive conditions expressed satisfaction with the program, but regretted that worsening health prevented them from taking further advantage of the increased opportunities made possible by the Pilot.

## E. Employer-employee relationships

The direct funding arrangements introduced through the Pilot established an employer-employee relationship between self-managers and attendants, where typically there had been a client-service provider relationship in a number of situations involving exactly the same people. There were a number of outcomes related to changes in these relationships.

### Profile of attendant workers

Over two-thirds of self-managers surveyed report that they have hired at least one former attendant.

Figure 21. Self-Managers' Recruitment of Former Attendants

	Selected in 1995		Selected in 1996		All respondents	
	Frequency	%	Frequency	%	Frequency	%
hired at least one former attendant	41	71	15	71	56	71
hired all new attendants	17	29	6	29	23	29
Total	58	100	21	100	79	100

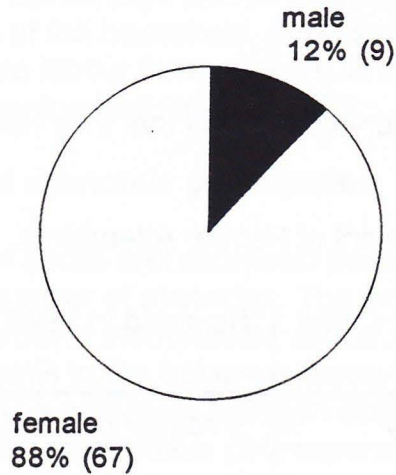
• Three self-managers selected in 1996 reported that they intend to begin spending funds allocated to them in January 1997, and so therefore were excluded from this table.

Most self-managers selected in 1995 have hired women as their main<sup>9</sup> attendant workers: sixty-seven out of the seventy-eight respondents to the attendant worker survey identified themselves as women.

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<sup>9</sup> The survey of attendant workers was directed to the two attendants who worked the most number of hours for each self-manager. See the appendix describing the methodology for this evaluation for further details.

Figure 22. Gender of Main Attendant Workers



The mean age of the respondents was thirty-four and their median age is thirty-two. The youngest respondent to the attendant worker survey was nineteen and the oldest was sixty-two. Approximately one-third are aged thirty to thirty-nine.

Figure 23. Age of Main Attendant Workers

	Frequency	%	Cum. %
19-24	14	19	19
25-29	15	21	40
30-39	24	33	74
40-49	14	19	93
50-62	5	7	100
Total	72	100	

• Five respondents declined to provide their age.

As the following table indicates, respondents to the attendant worker survey are a diverse group in ethno-cultural terms. Twelve identified themselves as members of a visible minority, three identified themselves as aboriginal, ten reported that one of their parent's first language is French, eight reported that at least one of their parent's first language is neither English nor French, and fifty-one reported that at least one of their parent's first language is English.

Figure 24. Ethno-Cultural Background of Main Attendant Workers

	Frequency	%	Cum %
parent's first language neither English nor French	8	10	10
parent's first language French	10	13	23
visible minority	12	16	39
aboriginal	3	4	43
parent's first language English	53	69	112
N	78		

• Percentages and frequencies exceed 100% and N respectively, as these variables were asked as part of a multiple-response question.

Seventy-four out of seventy-eight respondents to the attendant survey report that they have at least some post-secondary education. Seventeen have completed a university degree.

Figure 25. Post-Secondary Education Attainment of Main Attendants

	Frequency	%	Cum %
no post-secondary education	4	5	5
begun post-secondary program	17	22	27
completed certificate or diploma	40	52	79
completed university degree	17	22	100
Total	78	100	

The mean number of hours worked per week for the self-manager is seventeen.<sup>10</sup> Although not explicitly asked about whether they prefer to work on a full-time or part-time basis, some attendants presently employed part-time commented that they wish to find full-time employment. A number of attendants surveyed have more than one employer in this field. Twenty-four respondents to the attendant worker survey (31%) report that they also work for an agency that delivers services to people with disabilities and nine others (12%) indicate that they work for more than one self-manager.

Figure 26. Number of Hours per Week Worked by Main Attendants

	Frequency	%	Cum. %
less than 10	20	27	27
10-15	27	36	64
16 or more	27	36	100
Total	74	100	

Self-managers selected in 1995 employ, on average, three attendants, including those who work exclusively in a back-up capacity. However, nine report that they have only one attendant, and fourteen report that they have five attendants or more.

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<sup>10</sup> The figure on typical number of hours worked refers to the typical number of hours worked for the self-manager who gave the survey to the attendant worker. See appendix describing the methodology for further details.

Figure 27. Number of Attendants Employed by Self-Managers Selected in 1995

	Frequency	%	Cum. %
1	9	15	15
2	13	21	36
3	15	25	61
4	10	16	77
5	5	8	85
6	7	11	97
10	1	2	98
11	1	2	100
Total	61	100	

Forty-one self-managers selected in 1995 indicate that they have at least one attendant who works more than twenty hours per week. Sixty-three have at least one attendant who works fewer than ten hours per week, including those who work exclusively in a back-up capacity.

Figure 28. Self-Managers Selected in 1995 by their Attendants' Typical Weekly Hours

	Frequency	%	Cum %
at least one attendant works 30 hours or more	19	30	30
at least one attendant works 20-30 hours	22	35	65
at least one attendant works 10-19 hours	35	56	121
at least one attendant works fewer than 10 hours	35	56	176
at least one attendant works in a back-up capacity only	28	44	221
<b>N</b>	<b>63</b>		

• Frequencies and percentages exceed N and 100%, respectively, as these variables were part of a multiple-response question.

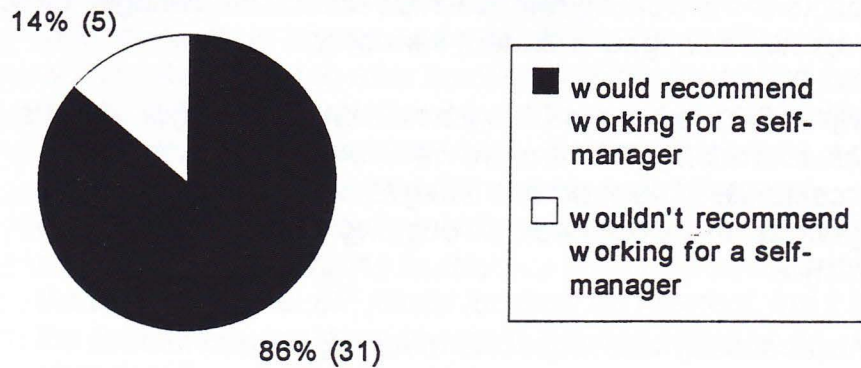
### Working relationships, working conditions and job satisfaction

Both self-managers and attendants pointed to improvements in direct accountability of the attendant to the self-manager, a more mutually respectful relationship and increased flexibility for both self-manager and attendant<sup>11</sup>. Of the twenty-four attendants who worked for an agency in the year preceding the Pilot, 86% would recommend working for a self-manager.

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<sup>11</sup> Twenty-two of the respondents to the follow-up survey of participants selected in 1995 indicate improved working relationships with attendants since becoming a self-manager. Nine out of the twenty-one participants selected in 1996 who have begun spending their funds also reported improved working relationships with attendants, even though they had only been self-managing for a few months when surveyed. All other respondents indicated that there had been no change in their working relationships with attendants. That is, no one indicated that their working relationships with attendants had worsened.

Figure 29. Recommend Working for a Self-Manager



• This figure displays whether or not attendants who worked for an agency in the year preceding the Pilot would or would not recommend working for a self-manager (N=24).

These attendants identified the following benefits of working for self-managers rather than for agencies:

- more flexibility
- better working relationship
- less bureaucratic, deal directly with self-manager
- more appreciation for services performed
- more consistency
- more organized
- safer, more secure working environment
- fewer conflicts
- better communication
- no office gossip or complaints from co-workers
- self-manager happier, more independent
- self-manager in better health
- fewer people entering individual's home
- more hours

On the whole, attendants are satisfied with their jobs, whether or not they have worked for an agency in the past. Sixty-one of the respondents to the attendant worker survey (81%) indicate that they are very satisfied, and twelve (16%) reported that they are generally satisfied. Two (3%) indicate that they are not at all satisfied.<sup>12</sup>

Many self-managers and attendants commented in the surveys and in the interviews on the positive aspects of the working relationships under self-managed direct funding, as compared with agency-managed attendant services.

*"My self-manager and I have an alternative lifestyle. We are able to work together and we have an understanding and acceptance of each other's lifestyle. Working with other agencies, there has been an ongoing issue about my lifestyle."*

*"Accountability and respect is much higher and there is loyalty and commitment."*

*"I know I can resolve issues. I find there is greater accountability between my attendants and me."*

*"Before becoming a self-manager, attendants seemed to have much less regard for my well-being. Their job was often poor because they did not have to answer to me."*

*"I have found this form of employment to be extremely satisfying. The level of respect, responsibility, and dedication by my self-manager has far exceeded [that of] any agency. This program has also been beneficial to my physical health. I have not experienced any migraines under these working conditions - having gone from 12 per year to none to date."*

*"I find the work I do for my employer very rewarding and much appreciated."*

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<sup>12</sup> The attendant worker survey included measures of job satisfaction that would enable comparison to a sample of workers providing analogous services to seniors. Compared to this group, the attendants employed by self-managers in this Pilot are more satisfied with their jobs (Neysmith and Nichols 1994). On every variable included in the index of job satisfaction (e.g., openness of communication, spirit of cooperation, salary and equitable treatment of staff), the attendants indicated greater satisfaction.

*"I work for [a residential service agency] also as a support worker, and I feel very limited in what I'm allowed to do. With the self-manager, I am talking to THE boss if changes need to be made."*

*"I have worked . . . as an attendant for nine years in various settings – SSLUs, Outreach, meetings and now independently in homes and workplaces. I recently quit working for Outreach after four increasingly frustrating years of employment. My relationships with clients were excellent but the policies, procedures, rules, red tape, blue tape, purple tape, etc. as well as the various controlling and conflicting personalities in middle and upper management all made it too exasperating to stay . . . Working one-on-one is the answer for me. DF [direct funding] isn't perfect, but it is the best employment environment I've had so far as an attendant."*

The survey points to a number of factors<sup>13</sup> associated with those attendants who indicate the highest level of job satisfaction including:

- provision of training
- scope of orientation
- management qualities (clear direction, constructive criticism, addressing concerns and soliciting feedback)

Despite the overall improvement in working relationships, working conditions and job satisfaction, some significant difficulties were identified by both self-managers and attendants.

The following drawbacks of working for a self-manager were identified by attendants who worked for an agency in the year previous to being hired by a self-manager under the Pilot Project:

- no health benefits
- fewer hours
- ceiling on income

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<sup>13</sup> When variance in the job satisfaction index was analyzed against these factors, they were found to be statistically significant ( $p > 0.01$ ). Those with the lowest level of job satisfaction tended to be younger, and working in the northwest and northeast regions of the province.

- no job security
- no support network for the worker
- no guidelines on safety
- short shifts
- lack of advance planning, inadequate scheduling

In addition, some self-managers and attendants reported conflicts over issues such as working conditions, disputes over duties and personality differences (see section below on retention of employees for further details). One detailed allegation of sexual harassment by a self-manager was brought to the attention of the evaluation team by an attendant. Two attendants questioned whether the employer is following the guidelines for the Pilot on attendant duties. A couple of attendants felt that the self-manager was taking advantage of the attendant in requests for additional tasks and emotional support beyond what the attendants understood to be a part of their job description.

It should be noted that drawbacks identified by some attendants contradict benefits reported by others. For instance, some attendants report fewer hours as a drawback experienced working for a self-manager, while others report that one of the benefits of working for a self-manager is that they work more hours. This situation suggests that working conditions vary among employers, be it a self-manager or an agency.

## Recruitment and retention of staff

Self-managers identified a number of qualities they considered important to look for in recruiting attendants:

- versatility and flexibility
- ability to listen
- being respectful and having positive attitudes towards persons with disabilities
- understanding the nature of assistance in its broadest sense
- not concerned with becoming a friend, but friendly
- not intimidated by personal physical tasks like bathing
- responsible and punctual
- able to take direction and follow instructions
- able to pick up verbal cues
- doing what needs to be done
- a sense of humour and of enjoyment on the job

Self-managers used many methods for recruiting including Canada Employment Centres; newspaper job listings; bulletin boards in post-secondary institutions, hospitals and nursing homes; attendant rosters at ILRCs and word of mouth. Some self-managers experienced difficulties in recruiting attendants with qualities they felt important, citing the following:

- wage maximum is below that previously earned by attendants who previously provided services to the individual as employees of agencies
- hiring process takes a long time
- difficulty in recruiting staff for short periods of time (e.g., 1.5 hours)
- small population base from which to recruit;
- other attendant work opportunities come with a medical/dental plan

Thirty-seven of those selected in 1995 (59%)<sup>14</sup> reported turnover since January 1996. On average, two attendants left their employ. The main factors identified by self-managers that explained turnover include:

- inadequate performance (identified by nine self-managers)
- employee accepted another job offer (identified by ten self-managers)
- employee moved (identified by eleven self-managers)

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<sup>14</sup> Although people who use attendant services value stability and consistency in staffing arrangements (Metropolitan District Health Council Working Group on Services for People with Physical Disabilities 1996), high rates of staff turnover are commonly found in agency-managed systems .

- employee harassing, abusing, or exploiting someone (identified by seven self-managers)

Approximately one-quarter of the turnover occurred at the discretion of the self-manager due to inadequate performance.

## **F. Utilization and effectiveness of supportive resources**

The Pilot Project made available to self-managers a range of supportive resources through CILT, as the Pilot Administration and as a resource centre for self-managers in the Central East region, and through other Independent Living Resource Centres throughout the province. Manuals on self-management were produced and distributed to each self-manager. CILT and the other ILRCs provide information and support upon request. A newsletter has been distributed to participants, and participants have been invited to sign up for a network of self-managers.

In addition to their support to self-managers selected for the Pilot Project, CILT and other ILRCs also assisted non-selected applicants in improving their service arrangements where possible and requested. For example, one individual was assisted in applying for an SSLU and has now begun a college program; this individual was not selected due to difficulties with reading, writing and arithmetic.

CILT, as the Pilot Administration, and the ILRCs found that the funding that they received under the Pilot to provide to supportive resources was adequate to the task. Particularly in less densely populated areas, staff felt that additional resources for travel would have been helpful.

### **Satisfaction with CILT and other Independent Living Resource Centres**

Self-managers report a high level of satisfaction with the support provided through CILT.<sup>15</sup> The level of satisfaction is not as high with other centres.

Self-managers identified aspects of support from CILT as Pilot Administration they found particularly valuable:

- the helpfulness and timeliness of CILT staff in responding to requests for information

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<sup>15</sup> Fifty-three respondents to the follow-up survey of self-managers selected in 1995 (84%) and nineteen selected in 1996 (83%) reported that they are very satisfied with CILT.

- problem-solving assistance of staff
- specific assistance in setting up book-keeping and financial arrangements
- communications provided (e.g., newsletter)
- access to the toll-free number for assistance
- manuals for self-managers

The assistance provided by CILT and other Independent Living Resource Centres in their role as ILRCs for the Pilot Project was also highly valued, in particular:

- support of ILRC staff in addressing issues and providing information
- conference calls and meetings between self-managers
- workshops on managing attendants, and on Employment Standards Act attendant roster.

Self-managers generally found that having support available from an ILRC in their region was helpful. For example, because of the support from local ILRC staff, two self-managers who had been hospitalized were able to return home with attendant support rather than remaining in the facility or moving to supportive housing. However, a couple of self-managers found that the ILRC in their region was not sufficiently informed about the Pilot to provide needed assistance, and so they went directly to CILT as Pilot Administration for the support and information they required.

A number of areas were pointed to for further development and support by CILT and ILRCs:

- streamlined reporting procedures, including on-line filing capability
- rostering of recommended attendants
- assistance in managing personnel issues
- general management skills (e.g., time management and scheduling)
- direct deposit of the advances to self-managers' direct funding bank accounts
- additional workshops on issues related to self-managing (e.g., communicating with attendants)
- additional supportive resources (e.g., videos on self-management)
- brokering for self-managers (in hiring attendants, arranging book keeping)
- finding accessible housing
- provision of training for potential attendants (especially in northern and rural communities)
- information on available assistive technologies

It might be assumed that those self-managers indicating a desire for additional support would be those with lower scores on the scale measuring self-management skills.

However, this does not appear to be the case. Those who indicate they would benefit from additional support from ILRCs were not predominantly those with below-average scores on this scale.

### **Facilitation of networking among self-managers**

The Project has invested in enabling peer support to occur among self-managers through such efforts as development of a sign-up sheet for a self-manager network and hosting gatherings at some ILRCs. However, thirty-eight (60%) of respondents to the follow-up survey of self-managers selected in 1995 report no contact with other self-managers. Nonetheless, when the self-managers were asked what would improve their experience, the most common response was more contact and interaction with other self-managers. They pointed to a number of ways in which the Project could facilitate this broader networking and connections:

- home page on the World-Wide Web
- e-mail network
- more frequent gatherings hosted by ILRCs with more advance notice
- provincial and national conferences of self-managers
- a mentoring system for new self-managers

### **Support to attendant workers**

The concerns raised by attendants suggest a need to develop a more focussed response to the support needs and issues of attendant workers. Some attendants reported feeling isolated and unsure of whom to contact in the event of a disagreement with self-managers over employment-related issues, or if they believed that the self-manager was not adhering to the Pilot Project's policies. One attendant who felt that both self-managers and attendants could benefit from additional support in managing working relationships under self-managed direct funding stated:

*"A support system could help attendants not reach the burn-out point while at the same time not undermining the socio-political struggle persons with disabilities have been in."*

## **G. Responsiveness of the Pilot**

The Pilot Project was envisioned as a response to consumer demands and aspirations for greater control in their lives, and for greater opportunities to contribute to and be included in their communities. The Project put in place a number of procedures and

mechanisms to enable ongoing responsiveness to self-managers and their individual requirements. The research points to a number of outcomes in this regard.

### **Responsiveness to individual needs**

One indicator of responsiveness is the wide range of hours approved for self-managers, ranging from fewer than sixty hours per month to 180, the maximum. The Project also enabled attendant services to be provided that varied substantially in the range of tasks performed.

Some mechanisms have been established to respond to changes in needs for hours including a contingency fund and a means for responding to requests for increased hours and budget. (See discussion of funding in the section on choice, flexibility and control). One self-manager interviewed for the evaluation, whose advance had been "clawed-back" because the previous quarterly report showed that not all allotted funds had been used, believed that the change was permanent. In other words, this individual was under the impression that if usage dipped below the number of hours approved, then the Project Administration would permanently reduce the amount of subsequent advances. This situation caused the individual some distress. The individual seemed unaware that the Project Administration "clawed-back" only enough funds in any one quarterly advance so that the individuals had a maximum of two months of surplus plus enough funds to cover three months of attendant services in their direct funding bank accounts. Should an individual require all approved hours in the future, the amount of the advance would revert to the level approved.

Another indicator of the Pilot's responsiveness to individual need is the accommodation of variance in self-management experience. As detailed in the preceding section, staff at CILT and the other ILRCs assisted participants by providing information and other resources to enable a smooth transition to self-management and mutually satisfying employer-employee relationships under the Pilot. Some required and desired more assistance than others. Even though participants were selected only if they could demonstrate self-management capacity, the opportunity to receive direct funding for attendant services appears to have rapidly brought about a greater capacity to self-manage. After self-managing their attendant services for at least two months, sixty-six of the participants surveyed (80%) reported that their management skills had improved. Those who did not report that their management skills had improved tended to be those who self-managed their attendant services under other direct funding mechanisms prior to participating in the Pilot and to be those who had held managerial positions in the labour force.

## **Administrative responsiveness**

CILT is monitoring the funds, and mechanisms have been put in place to reduce transfers to self-managers if requirements decrease, or if allocated hours have not been used; a maximum of two months of surplus plus three months of budget is available to a self-manager at any one time.

A few attendant workers believed that the monitoring mechanisms could be strengthened to address alleged irregularities. For example, two respondents to the attendant survey reported that a self-manager paid them for hours not received and banked the unused hours to draw upon in the future. Another attendant alleged that a self-manager had hired an immediate family member.

## **Systemic responsiveness of the Pilot Project**

In addition to responding to the needs of particular individuals, the Pilot has also had an impact on services and supports more generally. Impacts included:

- attendant services made available in less populated areas where Outreach and SSLU systems do not exist;
- services made available in minority languages (e.g., French and Italian); and
- more effective and efficient use of health care services (see section on cost-effectiveness).

## **H. Cost-effectiveness**

While the survey instruments did not ask respondents about cost-effectiveness *per se*, a number of self-managers, ILRC representatives and attendants commented that they regarded the Pilot Project as a cost-effective initiative:

*"It's a really great program. Things are only going to get better. It's cost-effective as well, because it eliminates the middle-man. Funding is portable; it's attached to me."*

*"It's a lot cheaper for the government in the long run, and things are better for me this way. If anything happened to my husband, I wouldn't want to end up in an institution."*

*"CILT staff gently and cheerfully guided me on a road that has saved my life and the government hundreds of thousands of dollars."*

*"It is my belief that in spite of the increased services I receive through Direct Funding, the per diem cost of providing assistance to me has decreased due to lower administration costs."*

*"I think that the program is an excellent opportunity to cut costs to agencies that have unnecessary overhead. There appears to be more need for this type of program."*

*"I personally would support making this Project permanent. It would save the government a great deal of money and it gives the disabled person independence."*

These perceptions are borne out by the quantitative analysis of cost-effectiveness outlined in detail below. The analysis presented demonstrates that the Pilot represents a cost-effective alternative to agency-managed attendant service delivery for this group of participants. The unit cost is lower, the benefits outweigh any drawbacks, and self-managed attendant services has also led to savings through more efficient use of health care services. The numbers of people who report receiving health care services has increased slightly, but per capita and total costs have declined. Given the importance of timely treatment for long-term health and well-being, the stability in the numbers of people who reported that they received health care services in 1996 and in 1994, the comparison year, is a positive sign.

### **Comparative unit costs**

In determining the cost-effectiveness of the Pilot Project relative to comparable programs, it was necessary to calculate each system's unit cost. The comparable systems are Outreach Attendant Services and Support Service Living Units (SSLUs). The unit cost is the amount required for one hour of attendant service under each of these programs.

Figure 30. Direct, Administrative and Total Unit Costs for the Pilot Project

1995-1996	Self-Managers	Administration	Total
total expenditures	\$1,691,135	\$299,959	\$1,991,094
total hours	122,282	122,282	122,282
UNIT COST	\$13.83	\$2.45	\$16.28

The unit cost for the Pilot is \$16.28, \$2.45 (15%) of which is spent on administration. The administration cost consists of the amounts spent by the Project Administration (CILT) and the other Independent Living Resource Centres under the Pilot. The unit costs for the Outreach and SSLU systems are \$24.29 and \$33.79, respectively.

Figure 31. Unit costs for the Pilot Project, Outreach and SSLUs

1995-1996	Pilot	Outreach	SSLU
N	78	1,684	1,189
total expenditures	\$1,991,094	\$16,081,679	\$39,763,511
total hours	122,282	662,093	1,176,829
UNIT COST	\$16.28	\$24.29	\$33.79

- The Pilot figures were derived from the actual program expenditures and the number of hours used from 1 April 1995 to 31 March 1996, subtracting the amount allocated for the evaluation from the administrative cost.
- Total expenditures and total hours for Outreach Attendant Services and Support Service Living Units were obtained from the Ontario Ministry of Health. Those programs that have reported number of paid hours (e.g., including on-call time) rather than number of hours actually delivered have been excluded. In total, the excluded programs account for annual Outreach funding of \$4,458,592 and annual SSLU funding of \$3,910,024.
- The figures for the total number of clients served by these systems were obtained from the Ontario Ministry of Health, excluding those programs which reported paid rather than actual hours. In total, the excluded programs account for 387 Outreach clients and 234 SSLU clients.

The cost of one hour of attendant service varies substantially between the three systems, even though the average wages paid do not.<sup>16</sup> However, not *all* individuals presently receiving services from Outreach or within an SSLU could have participated in the Pilot Project at this unit cost. The same management savings could not be achieved with all individuals who presently receive services through the Outreach and SSLU systems.

### **Cost-effectiveness ratios**

In order to determine the relationship between the overall benefits and unit costs, net benefits were measured. The next four tables summarize the scores on the variables selected for inclusion in the measure of net benefits.

In calculating the net benefit score for each individual, the scores on the variables listed in the table entitled "Drawbacks of Self-Managed Direct Funding" were subtracted from the scores on the variables listed in the table entitled "Benefits of Self-Managed Direct Funding" plus the score on "Differences in Self-Reported Health Status."

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<sup>16</sup> Many Outreach and SSLU employees have a medical/dental private insurance plan, which the Pilot Project did not provide. While coverage and premiums vary, it would be unusual for such plans to cost in excess of 5% of employees' wages. Employers may cover some or all of these costs.

Figure 32. Benefits of Self-Managed Direct Funding

	Selected in 1995				Selected in 1996	
	Experienced at time of first survey		Experienced since January 1996			
	Frequency	%	Frequency	%	Frequency	%
choice in attd svcs	50	86	22	35	17	81
choice overall	47	81	39	62	19	90
control over attd svcs	50	86	29	46	20	95
control overall	49	84	34	54	21	100
management skills	46	79	38	60	20	95
independence	49	84	37	59	20	95
personal comfort	47	81	41	65	16	76
social, leisure activities	37	64	31	49	11	52
relations with family, friends	28	48	20	32	9	43
relations with intimate partner	20	34	15	24	8	38
participation in education	8	14	10	16	3	14
employment opportunities	13	22	17	27	5	24
ability to travel	17	29	27	43	14	67
working relationships with attds	not asked		35	56	9	43
access to health-related svcs	not asked		11	17	12	57
N	58		63		21	

- This table excludes the three participants selected in 1996 who indicated that they planned to begin spending their funds in January 1997.
- None of the respondents indicated a decrease or worsening in these areas.

More than half of respondents to the follow-up survey of self-managers selected in 1995 indicated that their health has improved. Two of the three individuals who indicated a decline in their health status attribute this decline to a progressive disability resulting in the need for attendant services, and the other individual reported a deterioration in health status unrelated to the disability resulting in the need for attendant services.

Figure 33. Difference in Self-Reported Health Status

	Selected in 1995		Selected in 1996		All respondents		
	Frequency	%	Frequency	%	Frequency	%	Cum %
-2	1	2	1	5	2	2	2
-1	2	3	0	0	2	2	5
0	27	43	3	14	30	36	40
1	21	33	10	48	31	37	77
2	6	10	6	29	12	14	92
3	5	8	0	0	5	6	98
4	1	2	1	5	2	2	100
Total	63	100	21	100	84	100	

• The three self-managers selected in 1996 who had not begun spending their funds at the time of the survey have been omitted from this table.

Self-managers indicated that they have experienced a few drawbacks as a result of participating in the Pilot, though the drawbacks appear to be most evident in the first few months of self-managing. In some cases, self-managers indicated that a particular potential drawback did not apply to them (e.g., having to move).

Figure 34. Drawbacks of Self-managed Direct Funding

	Selected in 1995				Selected in 1996	
	Experienced at time of first survey		Experienced since January 1996			
	Frequency	%	Frequency	%	Frequency	%
sole responsibility for attd svcs	7	12	3	5	2	10
legal liability as employer	5	9	3	5	1	5
book-keeping	8	14	7	11	7	33
personnel management	11	19	5	8	1	5
invasion of privacy	7	12	5	8	2	10
conflicts with attds	6	10	5	8	1	5
changing attds	13	22	9	14	4	19
having to move	2	3	2	3	1	5
N	58		63		21	

In order to determine net benefits for each individual participant selected in 1995, it was necessary to assign scores to those who did not respond to the first survey and/or the follow-up survey. It was also necessary to anticipate what the scores for those selected in 1996 would be, if they were surveyed again in eight months time.

The most conservative approach is to assume no change, and thus assign a score of zero to those for whom data are not available. (See Figure 35.) However, it is reasonable to assume that those who did not respond experience, on average, the same number of benefits and drawbacks as those who did. It is also reasonable to assume that those selected in 1996 will experience, on average, the same number of benefits and drawbacks as those selected in 1995.

Therefore, a second net benefit measure in which the mean number of benefits and drawbacks have been assigned to those who did not respond has also been calculated (See Figure 36.) The net benefit scores listed in Figure 35 and Figure 36 clearly demonstrate that most participants felt that the benefits of direct funding outweighed any drawbacks experienced as a result of participating as a self-manager in the Pilot Project.<sup>17</sup>

<sup>17</sup> Details on the construction of these indices and tests conducted to verify their quality may be found in the appendix describing the study's methodology.

Figure 35. Net benefit (NB<sub>0</sub>) Scores

Score	Frequency	%	Cum. %	Z-Score
-11	3	3	3	-2.12
-10	1	1	4	-2.01
-7	1	1	5	-1.68
-5	2	2	7	-1.46
-4	2	2	9	-1.34
-3	3	3	12	-1.23
0	11	11	23	-0.90
1	3	3	26	-0.79
2	5	5	31	-0.68
3	5	5	36	-0.57
4	2	2	38	-0.46
5	5	5	43	-0.34
6	3	3	46	-0.23
8	5	5	52	-0.01
9	4	4	56	0.10
10	2	2	58	0.21
11	5	5	63	0.32
12	4	4	67	0.43
13	4	4	71	0.54
14	1	1	72	0.66
15	7	7	79	0.77
16	3	3	82	0.88
17	2	2	84	0.99
18	2	2	86	1.10
19	1	1	87	1.21
20	3	3	90	1.32
21	2	2	92	1.43
22	2	2	94	1.54
23	2	2	96	1.65
24	1	1	97	1.77
25	1	1	98	1.88
26	2	2	100	1.99

• Mean: 8.10; Median: 8.20; minimum: -16; maximum: 32

• This table excludes those selected in 1996 who had not yet begun spending their funds (3 participants).

Figure 36. Net benefit (NB<sub>M</sub>) Scores

Score	Frequency	%	Cum. %	Z-Score
2	1	1	1	-1.97
3	5	5	6	-1.77
4	1	1	7	-1.58
5	2	2	9	-1.38
6	2	2	11	-1.18
7	1	1	12	-0.98
8	2	2	14	-0.79
9	3	3	17	-0.59
10	36	36	54	-0.39
11	4	4	58	-0.19
12	6	6	64	0.00
13	6	6	70	0.20
14	5	5	75	0.40
15	8	8	83	0.60
16	3	3	86	0.79
17	1	1	87	0.99
18	2	2	89	1.19
19	1	1	90	1.39
20	3	3	93	1.58
21	1	1	94	1.78
22	1	1	95	1.98
23	1	1	96	2.18
25	1	1	97	2.57
26	3	3	100	2.77

• Mean: 11.98; Median: 10.40 , minimum: -16; maximum: 32

• This table excludes those selected in 1996 who had not yet begun spending their funds (3 participants).

Given that data from both the first and follow-up surveys of self-managers selected in 1995 are available, it was necessary to verify that net benefit scores for those selected in 1995 did not vary significantly from the net benefit scores for those selected in 1996. Otherwise, an analysis that included the net benefit scores for those selected in 1996 would be inappropriate. As the table below indicates, the mean score on the more conservative measure of net benefits ( $NB_0$ ) for those selected in 1996 is only slightly less than the mean score for those selected in 1995, and the range of scores is similar.

Figure 37. Net Benefit ( $NB_0$ ) by Year of Selection

	Frequency	High	Low	Mean
Selected in 1995	78	26	-11	9.12
Selected in 1996	21	24	-10	8.73
Total	99	26	-11	7.92

- t is not significant
- This table excludes those selected in 1996 who had not begun spending their funds (3 participants).

In examining the impact of the Pilot Project on participants, it was important to establish whether source of services prior to the Pilot accounted for variance in net benefit scores. This analysis was particularly pertinent in light of the fact that prior to their participation in the Pilot, nine individuals self-managed funding for their services and nine participants relied entirely upon unpaid support. Therefore, the variance in the more conservative net benefit measure ( $NB_0$ ) was analyzed in relation to these characteristics.

Figure 38. Net Benefit ( $NB_0$ ) by Self-Management Experience Pre-Pilot

	Frequency	High	Low	Mean
VocRehab, OIC or Private Insurance	14	24	-11	6.36
Other (paid and/or unpaid)	81	26	-11	8.65
Total	95	26	-11	7.92

- t is not significant
- This table excludes those selected in 1996 who had not yet begun spending their funds (3 participants) and those selected in 1995 who responded anonymously to one or both surveys (4 participants)

This analysis indicates that, on average, those who were self-managing their attendant services prior to the Project experienced fewer net benefits than those who were not. However, the mean net benefit score for those who were self-managing prior to the Pilot is not much lower. In other words, the Pilot Project has provided a mechanism for self-managed attendant services that is regarded as more beneficial, on average, than other direct, individualized funding mechanisms for self-managed attendant services that are available to some people in Ontario.

Figure 39. Net Benefit (NB<sub>0</sub>) by Exclusive Reliance on Unpaid Support Pre-Pilot

	Frequency	High	Low	Mean
Unpaid services ONLY	9	13	-5	4.56
Paid svcs OR paid & unpaid svcs	86	26	-11	8.71
Total	95	26	-11	7.92

• t is not significant

• This table excludes those selected in 1996 who had not yet begun spending their funds (3 participants) and those selected in 1995 who responded anonymously to one or both surveys (4 participants).

The data summarized in the table above indicate that those who received unpaid services *only* prior to the Pilot Project have *not* experienced significantly more benefits or drawbacks from participation than those who were receiving paid services prior to participation: both groups experienced similarly high levels of net benefit from participation. This suggests that the benefits of participation are not due exclusively to access to paid service or to an increase in paid service: other features of the self-managed direct funding mechanism are critical.

Since the unit cost is lower and most participants have positive net benefit scores, even using most conservative measure, it is evident that the Pilot has succeeded in enabling the participants to receive the attendant services that they require in a more cost-effective manner than through either the Outreach or SSLU systems. Considering the net benefits resulting from participation in the Pilot in relation to costs enables a more comprehensive evaluation of the overall cost-effectiveness of the Pilot than considering net benefits and costs in isolation. The next figures summarize the relationship between net benefits and unit costs in terms of effectiveness-cost ratios for the participants in the Pilot, SSLU and Outreach systems.

Figure 40. Comparative Effectiveness-Cost Ratios for Pilot, Outreach and SSLUs

Pilot	N	NB <sub>o</sub> /Unit Cost	NB <sub>w</sub> /Unit Cost
mean	95	0.51	0.74
mean Outreach candidate	37	0.46	0.72
mean SSLU candidate	58	0.55	0.76
mean Outreach pre-Pilot	47	0.55	0.77
mean SSLU pre-Pilot	13	0.37	0.68

Agency-delivered	1/Unit Cost
SSLU	0.03
Outreach	0.04

- Note that these ratios indicate rank order. They are meaningful only as comparative measures. For instance, a score of 0.3 indicates greater cost-effectiveness than a score of 0.03, not that it is ten times as cost-effective.
- The effectiveness-cost ratios for the Pilot were calculated by dividing the two net benefit ratios by the unit cost (\$16.28)
- The data on receipt of services from Outreach or SSLU were drawn from participants' application forms.
- Representatives from CILT and the Ministry of Health, each very familiar with the eligibility criteria for these two programs and each a member of the steering committee and of the evaluation sub-committee, determined whether each participant would best be considered an Outreach or SSLU candidate. In order to be eligible for the Pilot, applicants had to be eligible for Outreach and/or SSLU services.
- The effectiveness-cost ratios for SSLU and Outreach were calculated by dividing the value one by the unit costs for these two systems (\$33.79 and \$24.29, respectively).
- This table excludes those selected in 1996 who had not yet begun spending their funds (3 participants) and those selected in 1995 who responded anonymously (4 participants).

Even using the most conservative estimates of net benefits for the individuals in the Pilot to calculate a cost-effectiveness ratio (i.e., score on NB<sub>o</sub> divided by unit cost), it is more cost-effective than either SSLU or Outreach systems for this group of people. Fewer dollars are spent in total for each hour of service because a much greater proportion of the allocated funds are spent on direct service. With a lower unit cost, individuals experience far greater net benefits.

In addition to positive net benefits at a low unit cost, the Pilot Project has also enabled more efficient use of existing health care services delivered in the community and in facilities.

**Potential savings from substituting attendant for Home Care services**

In the year preceding participation in the Pilot Project, forty of the participants reported using a total of 1764 hours of service per month delivered through Home Care.

Figure 41. Home Care Hours Received Per Month Pre-Pilot

	Frequency	%	Cum. %
0	62	26	26
1-9	4	7	33
10-29	14	26	59
30-59	7	13	72
60-89	12	22	94
90-119	1	2	96
120-159	1	2	98
180-204	1	2	100
Total	102	100	

The Direct Funding Pilot Project enabled participants to receive attendant services that could encompass the specialized services (e.g. catheterization and dressings) performed by professionals contracted or employed by Home Care agencies prior to the Pilot Project. On an annual basis, if all hours were substituted and all were nursing hours, the maximum estimated potential cost savings to be realized by this substitution for these forty individuals would approach \$400,000.<sup>18</sup>

<sup>18</sup> Most individuals who received services from Home Care prior to the Pilot Project received a combination of home-making and nursing services. The application form, from which the data on the number of Home Care hours are drawn, did not ask applicants to distinguish between these two services. Therefore, it is not possible to determine with accuracy the cost savings achieved as a result of this Project from reduced use of Home Care services. Under the Pilot Project, however, participants could not use a combination of direct funding and Home Care or any other public funding source to exceed 180 hours of attendant services. Exceptions were made for people who use ventilators on a twenty-four hour basis to assist with breathing, and who therefore require in excess of 180 hours of attendant services per month

Figure 42. Potential Savings from Substituting Directly Funded Attendant Services for Home Care

N	Pre-Pilot monthly Home Care hours	Home Care average nursing hourly cost	Home Care average home-making hourly cost	Pilot hourly cost	Minimum estimated potential annual savings	Maximum estimated potential annual savings
40	1764	\$34.85	\$16.50	\$16.28	\$4,657	\$393,090

• Nursing and home-making hourly costs obtained from the Ontario Ministry of Health.

### Estimated savings from more efficient use of health care services delivered in facilities

In addition to these potential savings, the research findings indicate that the Pilot has enabled participants selected in 1995 to use services provided in health care facilities more efficiently in 1996 than was the case in 1994, reducing per capita and total costs and enabling self-managers to live fuller lives.

From reported usage at the time of the follow-up survey (N=63), it appears that the number of the respondents who used emergency hospital services in 1996 increased by over 40% compared to 1994, but the total number of visits rose by only 14%. That is, the average number of visits per person and the per capita costs of emergency services declined.

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(2 participants, 1 Home Care client). All participants could continue to receive publicly funded services besides attendant services. Thus, attendant services were not substituted for all Home Care nursing services used by Pilot participants. However, based on interviews and the surveys of self-managers conducted for this evaluation, it appears that few self-managers who regularly received nursing services from Home Care prior to the Pilot continue to do so.

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Figure 43. Emergency Visits by Self-Managers Selected in 1995

	F	Total visits	Est. cost per visit	Min. est. cost	Max. est. cost
1996	16	44	\$38 - \$70	\$1,672	\$3,080
1994	9	38	\$38 - \$70	\$1,444	\$2,660

- source for minimum and maximum costs per visit: Ontario Ministry of Health
- Figures derived from authorized standard hospital rates for public hospitals in the Metropolitan Toronto District Health Council: downtown teaching hospitals \$54-70 per visit, other hospitals \$38-57 per visit
- 1996 figures drawn from follow-up survey (N=63). Responses were multiplied by a factor of 1.5 in order to project annual usage. Given that by the end of August 1996, 43 participants had returned their survey, the projected figure is a generous one.

From reported overnight stays to date in acute care hospitals, this group of sixty-three self-managers will have stayed an estimated sixty-four fewer nights in an acute care hospital in 1996 than in 1994. Therefore, per capita costs will decline and total costs declined for this group by at least \$19,000 and by as much as \$64,000.

Figure 44. Nights Stayed in Acute Care Hospitals by Self-Managers Selected in 1995

	F	Total nights stayed	Est. per diem	Min. est. cost	Max. est. cost
1996	9	101	\$300 - \$1,000	\$30,300	\$101,000
1994	11	165	\$300 - \$1,000	\$49,500	\$165,000

- source for minimum and maximum costs per visit: Ontario Ministry of Health
- Figures derived from authorized standard hospital rates for public hospitals in the Metropolitan Toronto District Health Council: community hospitals \$300 - \$ 500, hospitals with a teaching component \$500 - \$700, large teaching hospitals \$700 - \$1,000 +. That is, the maximum figure used in the above table is a conservative one.
- 1996 figures drawn from follow-up survey (N=63). Responses multiplied by 1.5 to project annual usage. Given that by the end of August 1996, 43 participants had returned their survey, the projected figure is a generous one.
- In comparing the data from 1994 and 1996, it is impossible to discern what role, if any, the trend towards quicker discharges played in the difference in the number of nights stayed.

It is estimated from the number of respondents who reported overnight stays in rehabilitation and chronic care facilities that four people stayed at least one night in such facilities in 1996, compared to six people in 1994. However, these participants

stayed an estimated total of 259 fewer nights in 1996 than in 1994. Therefore, per capita costs declined, and the total costs for this group declined by at least \$39,000.

Figure 45. Nights Stayed in Rehabilitation and Chronic Care Facilities by Self-Managers Selected in 1995

	F	Total nights stayed	Est. per diem	Min. est. cost	Max. est. cost
1996	4	315	\$ 150 - \$ 157	\$47,250	\$49,455
1994	6	574	\$ 150 - \$ 157	\$86,100	\$90,118

- Source for minimum and maximum costs per visit: Ontario Ministry of Health
- Figure derived from hospital restructuring project in the Metropolitan Toronto District Health Council: rehabilitation facilities \$ 150, chronic care facilities \$ 157
- 1996 figures drawn from follow-up survey (N=63). Responses multiplied by 1.5 to project annual usage. Given that the survey was administered in June 1996 and that 43 participants had replied as of the end of August 1996, the projected figures are generous.

Thus, the estimated total annual savings of reduced use of health care services delivered in health care facilities by this group is between \$53,000 and \$93,000. It is important to emphasize that these savings do not result from decreased use of health care services. In fact, ten respondents (16%) reported that they have received health care services previously unavailable or inaccessible to them as a result of their access to attendant services. None of these participants spent time in a health care facility during 1994 for intensive post-traumatic treatment.

Figure 46. Estimated Total Costs for Services Delivered in Health Care Facilities for Self-Managers Selected in 1995

	Freq.	Minimum estimated costs	Maximum estimated costs
1996	29	\$79,222	\$153,535
1994	26	\$137,044	\$257,778

- 1996 figures are generous projections (see tables above for further detail)

These figures on usage of services delivered in health care facilities appear even more dramatic when the impact of access to attendant services on admission and discharge decisions is taken into account. In 1996, it is estimated that access to attendant

services prevented admission at least once for eight self-managers,<sup>19</sup> and reduced length of stay at least once for eleven participants. In 1994, by contrast, lack of access to attendant services led to two participants being admitted at least once and extended the length of stay at least once for three participants.

Figure 47. Impact of Access to Attendant Services on Admission and Discharge Decisions for Self-Managers Selected in 1995

	1996	1994
access to attd svcs prevented admission	8	0
access to attd svcs reduced stay	11	0
lack of access to attd svcs at least partly responsible for admission	0	2
lack of access to attd svcs lengthened stay	0	3

- N=63, 29 of whom have received services in a health care facility in 1996 and 26 of whom received such services in 1994.
- Only those who had received services in a health care facility at least once during these years were asked if access to attendant services on admission and discharge decisions. That is, those who did not receive services in a health care facility were not asked if access to attendant services had reduced the need for health care services delivered in facilities. The figures on whether or not access to attendant services prevented admission should therefore be regarded as conservative.
- 1996 figures drawn from follow-up survey. Responses multiplied by 1.5 to project annual usage. Given that the survey was administered in June 1996 and that by the end of August 1996, 43 participants had replied, the projected figures are generous.

In addition, the Pilot Project has enabled at least fourteen self-managers selected in 1995 (22%) to receive services from their attendants while in a health care facility in 1996. Four self-managers selected in 1995 (19%) report that an attendant funded under the Pilot Project has provided services to them in a health care facility. Many of these self-managers reported that this feature made their stay much more physically comfortable and reduced their stress levels.

<sup>19</sup> Only those who had received services in a health care facility at least once during these years were asked if an attendant had provided services to them there. Twenty-nine participants selected in 1995 reported that they received services in a health care facility in 1996, and twenty-six of this group reported that they received services in a health care facility in 1994. Twelve participants selected in 1996 reported that they received services in a health care facility 1996 and fifteen of this group reported that they received services in a health care facility in 1994.

It is unlikely that attendants serving people in health care facilities constitutes double-payment by the Ministry of Health; once to the facility and once through the attendants' wages. Those who received services in a health care facility from their attendant funded under the Pilot, and who did not have a direct funding arrangement such as an Order-in-Council or private insurance for attendant services in the past, reported that, in previous stays, many of their needs were not met by hospital staff. Instead, they went without the assistance that they required, received assistance that was ineffectively delivered or relied mainly upon unpaid services provided by family or friends. In particular, the data suggest that staff in acute care facilities may find it difficult to meet the needs of people who require attendant services on a regular basis, in many cases for six hours per day or more, while also attending to the needs of other patients. Self-managers reported that attendants could also coordinate with nursing staff for improved in-hospital experiences and better rates of recovery, as illustrated by the following example:

*"I might have had to stay more than one night because of complications, but my attendant had extensive experience in this area . . . And so that helped when the nurses were having difficulty."*

In 1996, thirteen respondents selected in 1995 (21%) and two respondents selected in 1996 (11%) report that access to attendant services through the Pilot fostered recovery. By contrast, in 1994, one individual indicated that lack of access to attendant services obstructed recovery and another individual indicated that poor attendant services resulted in the use of emergency services.

## Summary and Conclusions

The *Self-Managed Attendant Services in Ontario: Direct Funding Pilot Project* has been highly successful in achieving its established goals. The fact that the initiative was designed and implemented attests to the persistence of numerous individuals and organizations in the independent living movement in Ontario over many years. The commitment of successive governments to the Project, and the efforts of many individuals in government both in the design phase and through ongoing participation in the Project's Steering Committee have been a key factor in its success.

Both in terms of numbers of people with disabilities who became self-managers of attendant services under this Project, and in terms of the number of organizations and players involved in the Pilot's implementation, the scale of the Project is substantial. A total of 102 individuals with disabilities from across Ontario received funding under the Pilot to employ attendant workers. The Centre for Independent Living in Toronto (CILT) acted as Pilot administrator, along with the eight other Independent Living Resource Centres throughout Ontario, created a network to provide information and resources to self-managers.

The evaluation of the Pilot Project examined the experience of self-managers, their attendants, and representatives of ILRCs in terms of eight key outcomes:

- establishing a consumer-driven partnership
- encouraging participation in the Pilot Project
- securing choice, flexibility and control over attendant services
- fostering social and economic participation
- creating effective employer-employee relationships
- enabling available and appropriate supportive resources
- promoting a responsive Pilot Project
- ensuring cost-effective provision of attendant services

Key achievements and challenges of the Pilot Project in relation to these goals are outlined below.

### Consumer-Driven Partnership

#### *Achievements*

The extensive involvement of consumer organizations with government departments and officials in all aspects of the Pilot is an example of partnership between government and non-governmental sectors that is a model of effective collaboration. Partners, including representatives of the Ministries of Health and Citizenship, the

Ontario Network of Independent Living Resource Centres, the disability community, and attendant workers. Over half of the Steering Committee was made up of individuals who use attendant services.

The partnership was effective not only in Project design and overall direction. Mechanisms were created under the Project for both consumers and government officials to work together in approving funding for participants, and in reviewing applications. The partnership was also successful in creating a predominantly consumer-driven process for selection of self-managers to participate in the Pilot, demonstrating that peer review was a valid and effective way of assessing needs for attendant services.

### *Challenges*

One area in which the partnership could be strengthened, is in the development of more opportunities to identify and address issues related to attendant workers. This would allow the partnership to anticipate issues that need to be addressed if the significant improvements in employer-employee working relationships, which the Project resulted in, are to be maintained.

### **Participation in the Pilot Project**

#### *Achievements*

The Pilot Project was very successful in encouraging and maximizing participation of a range of persons with disabilities within the eligibility criteria defined for the Project. Information about the Project was circulated widely, and steps were taken by ILRCs to raise awareness of the Project in their communities.

One aim of the Project was to ensure a "consumer mix" in the selection of participants ensuring adequate representation on the basis of a range and type of disability (defined by a range of need for hours), gender, region, ethno-cultural group, previous living arrangements and rural/urban location. By and large a representative mix was achieved in the group of those selected, when compared with other people with disabilities who would meet the eligibility criteria for the Project. However, the group selected is somewhat under-representative of the ethno-cultural diversity of the population (in particular aboriginal persons), and of the proportion of women who make up this population. Women made up 46% of the participants in the Pilot Project, and 5% of the participants surveyed reported that they are of a visible minority group. No one identified herself or himself as aboriginal. Future efforts to recruit self-managers for direct funding could consider more targeted outreach to these groups.

The majority of those who were selected into the Pilot found the selection process very fair, comfortable, informative and helpful in designing a schedule of attendant services to meet their needs.

### *Challenges*

A few concerns were raised about the eligibility criteria for determining who could participate in the Project, suggesting that both clarification and review of the basic criteria may be helpful before expanding the initiative. There was some variation in interpreting the criteria that self-managers could not live in SSLUs while in receipt of Direct Funding under the Pilot, with the result that some self-managers ended up staying in an SSLU building without receiving its services while others thought they had to move. The stipulation that SSLU residents had to make alternative arrangements within three months also proved unrealistic in some cases, given the difficulties in finding accessible housing, particularly at modest rents. Concern was also expressed that the emphasis on "stability" of participants' disabilities may disqualify them in the future if their condition deteriorated to the point that they need assistance in self-managing. Finally, it was suggested that the criterion of "self-management capacity," when understood exclusively as an individual exercise, might unnecessarily exclude people from the benefits of direct funding who could direct attendant workers and manage their funds with support.

A small proportion of selected participants found the selection process and interview intimidating. They felt that there was undue focus on providing justification for their proposed budget and on proving they were worthy as persons, not simply persons in need of attendant services. Further support to self-managers in preparing budget proposals prior to a selection interview may be one way of addressing these concerns.

Given the unmet demand for attendant services, and the growing interest by people with disabilities in obtaining direct funding, deciding the relative weight of need versus self-management capacity in determining who would get access to direct funding would be an ongoing challenge in any permanent program.

### **Flexibility, Choice and Control Over Attendant Services**

#### *Achievements*

The provision of direct funding to enable individuals to self-manage their attendant services had an indisputable impact on increasing their control over these services. In addition to the "statistically significant" relationship between direct funding and increased choice, flexibility, and control, self-managers spoke eloquently and profoundly of the difference that greater control made in their lives.

It enabled them to reprimand or fire staff who acted inappropriately or abusively. It brought them the power to decide when staff would enter their homes, at what times and for what reasons. It gave them greater privacy and control over their physical person. Many indicated that it ended their sense of vulnerability, fear, and insecurity at the hands of others.

There are many ways in which the quality of life of self-managers improved as they achieved greater control over their attendant services. Their sense of security improved, both personally and financially. Self-esteem, personal relationships and personal fulfilment all improved in substantive ways for many self-managers. Perceived improvements in both physical health and well-being were reported by a number of participants.

### *Challenges*

A few systemic challenges will need to be faced in order to sustain the positive impacts that came with direct funding. Self-managers reported a number of concerns with respect to funding, including lack of funding for employee medical/dental benefits and transportation, limitations on wage levels, caps on hours, managing accountability for funding and ensuring that direct funding will continue. It was suggested that limited wage levels and benefits packages is making recruitment of attendant workers more difficult for some self-managers.

## **Social and Economic Participation**

### *Achievements*

Increased social participation was also reported by self-managers in a number of areas including visiting informally with others, attending courses, attending religious services and shopping. At least ten self-managers attribute their current employment in either full or part-time jobs to participation in the Pilot and the flexibility that direct funding and self-management have brought. While the surveys did not examine the impact on household income and employment, three self-managers report that their spouse has been able to enter the paid labour force as a result of the provision and/or flexibility of attendant services under the Pilot. For the first time, some individuals are able to go on business trips and attend conferences, because their attendant service arrangements are flexible enough to allow this.

### *Challenges*

Significant obstacles to social and economic participation continue to be faced by the majority of participants, despite the increased choice and control they have in attendant services. In particular, self-managers identified inaccessible or unavailable facilities, services and programs, and the unmet need for assistance from others. Self-managed direct funding, it appears, opens many doors for individuals with disabilities, but other systemic responses to continuing barriers are still needed.

## **Employer-Employee Relationships**

### *Achievements*

Both self-managers and attendants point to the enormous difference that self-management and direct funding have made under this Pilot on the relationships

between them. In agency-delivered attendant services, the relationship is of client to service provider. The transformation to an employer-employee relationship has brought, according to the respondents for this evaluation, a much higher degree of mutual respect, accountability of attendants to individuals, more satisfying work for attendants and better communication. Attendants who have worked for agencies indicate a much higher degree of satisfaction in a number of areas. They point to a number of factors in the relationship with their new employer (i.e., a self-manager) that account for increased satisfaction: more flexibility, less bureaucracy, safer working environment, fewer conflicts, happier and more independent individuals and fewer people entering the individual's home.

### *Challenges*

Despite the overall improvement in working relationships and working conditions, attendants did point to some drawbacks they experienced in working for a self-manager including: no health benefits, lack of job security, limited wage levels, inadequate scheduling, lack of advance planning and difficulties in working out the relationship with an individual who is both an employer and someone to whom you are providing support.

These do not appear to be difficulties inherent in the provision of attendant services under self-managed direct funding, nor are the concerns universally shared. However, the fact that some attendants have these concerns affirms the conclusion above: that a more proactive means for identifying and addressing attendant worker issues could be provided. This does not mean that ILRCs should or would intervene in conflicts necessarily, but that additional resources might be developed to assist self-managers in their role, to provide more information to attendants and to develop training opportunities.

## **Provision of Supportive Resources**

### *Achievements*

The supportive resources that were provided by CILT to self-managers — including manuals to assist in self-managing funds and attendants, Project staff to respond to information requests, a newsletter on the Project, a toll-free telephone number — were found to be extremely helpful to the vast majority of self-managers. Other Independent Living Resource Centres were, for the most part, also acknowledged by self-managers for their support in problem solving, providing information about possible attendants, and arranging information sessions and workshops on self-management. The networking among self managers promoted and supported by CILT and other ILRCs was highly valued by participants.

### *Challenges*

Self-managers indicate that they want "more of the same" when it comes to support from ILRCs and CILT, with a particular emphasis on continued facilitation of networking and workshops on issues related to self-managing.

While self-managers would not give up the benefits of direct funding, there was a perception by some that additional supports in self-managing were needed. It was suggested that, in order to assist self-managers in dealing with the administrative load of self-management and the demands of recruiting staff, ILRCs might consider providing more direct support to self-managers. Provision of more direct supports in preparing budgeting proposals, in hiring staff, and in administration are not necessarily at odds with the concept of self-management. Such supports may in fact help to deal with challenges in working relationships reported by some self-managers and attendants.

### **Responsiveness of the Pilot Project**

#### *Achievements*

While the capacity to self-manage attendant services was one of the key eligibility criterion for this Pilot, people with a range of management experience were successfully included. The Pilot Project provided for a wide range of response to needs for attendant services, even if the cap on hours was considered by some to be too low. Guidelines for a contingency fund for self-managers strengthened the responsiveness of the funding arrangement by enabling a pool of reserves to be drawn upon when legitimately needed.

CILT has been responsive to the administrative requirements of direct funding. It has fostered the exchange of information with other ILRCs and has established a reporting system with a capacity to generate financial data and track participants' usage over time.

Finally, the Pilot has responded to broader systemic issues in attendant services by enabling the provision of attendant services in areas where SSLUs and Outreach are not available and in minority languages. Thus, direct funding has provided for a more equitable response to the need and demand for attendant services. The Pilot has also resulted in a more efficient use of health care services by self-managers.

#### *Challenges*

In order to ensure ongoing responsiveness, the experience of the Pilot suggests that some mechanism might be considered for a more proactive review of funding agreements and support arrangements to address changing conditions of a person's health or disability, seasonal fluctuation in need for those in rural areas, and in changing life circumstances. Monitoring mechanisms may need to be strengthened to

respond to a few allegations that self-managers are creating additional contingency funds by “banking” hours attendants did not work, but for which they were paid.

## **Cost-Effectiveness**

### *Achievements*

The cost-effectiveness analysis demonstrates that each hour of attendant service under self-managed direct funding costs less than an hour of service delivered in SSLUs and through Outreach services. There was more than 30% savings in costs per hour for attendant services through direct funding in this Pilot when compared to the cost per hour of delivering similar services through Outreach services, and 50 % savings in cost per hour when compared to delivering attendant services through SSLUs. These lower costs are associated with increased benefits for self-managers in terms of quality of life and improved health status.

In addition, the flexibility and control that self-managers obtained through direct funding appear to be associated with additional savings that came from substituting lower-cost attendant services for higher-cost Home Care services for a number of participants in the Pilot. Substitution of lower-cost attendant services was limited to the extent that self-managers could obtain a maximum of 180 hours of attendant services.<sup>20</sup>

Further, the research estimates significant savings to the public purse through more efficient use of health care services delivered in facilities. For self-managers surveyed, the average number of visits to emergency hospital services declined, and the number of overnight stays in hospitals also declined. Over 250 fewer nights were spent in rehabilitation and long-term care facilities by the participants, after becoming self-managers under this Project. These reductions are attributed by self-managers to greater availability of attendants in their home, improved overall health and the flexible schedules they could design with their attendants.

## **Conclusions**

In conclusion, the Self-Managed Direct Funding Pilot Project has achieved to a great extent the goals it established. The overwhelming support by participating self-managers and their attendants speaks to the success of this initiative. Their experience clearly demonstrates that by providing funds directly to individuals with disabilities who need services, and by enabling them to manage those services themselves, real advances can be made — in people’s personal lives, their social involvements and in their economic contributions.

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<sup>20</sup> Participants who require ventilators to breathe on a twenty-four hour basis could receive additional services from another publicly funded source, including Home Care. Two participants met this criteria, one of whom received the additional services from Home Care during the course of the Pilot.

This Pilot Project tested a particular model of direct funding for attendant services — self-managed direct funding. For the purposes of the evaluation, it is helpful to analyze why this Project has resulted, on average, in so many benefits with so few drawbacks. The few drawbacks experienced pertained to certain features of the Project, such as personnel management and book-keeping responsibilities. The fact that so few participants reported drawbacks, particularly once the transition phase was over, is quite remarkable.

Only those who could self-manage their attendant services were eligible for the Pilot, yet the participants' needs for management-related support did vary and, in many cases, participants' management skills improved during the course of the Pilot. Varying management support according to need implies varying administrative costs. The Pilot responded to variance in individuals' desire for management support by making funds available for this purpose to CILT and the other ILRCs across Ontario and by permitting individuals to contract out some management tasks, such as payroll.

The cost-effectiveness of self-managed direct funding demonstrated in this Pilot Project suggests that who controls how the funding is used *does* make a difference in the "costs of disability" to the public purse. Significant administrative savings were found on an individual basis for self-managers in this Project who had previously received attendant services from other publicly funded systems. Moreover, the findings for this evaluation indicate that investing scarce dollars in ways that enable and support people to exercise greater control in their lives, and in ways that allow them to pursue their own goals, improves health and well-being and diminishes demand on expensive public services such as health care.

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# Appendix #1: Methodology

The Roeher Institute designed this evaluation study with input from the Steering Committee and its Evaluation Sub-Committee. The Sub-Committee included a community services coordinator, Ministry of Health officials, a representative from the Ministry of Citizenship, a service provider who had worked as an attendant in the past and staff from the Centre for Independent Living in Toronto. Of the seven members of the Evaluation Sub-Committee, four use attendant services, three of whom became self-managers under the Pilot Project. As with the Steering Committee itself, consensus-building characterized the decision-making process in the evaluation sub-committee. The role of people with disabilities who use attendant services in the evaluation sub-committee was especially important given that research has often contributed to the marginalization of people with disabilities (Barnes 1996; Rioux 1994; Woodhill et al. 1992).

## **Evaluation framework**

Developing an evaluation framework was the first step in conducting this research Project. This framework served as the basis for analyzing the data, and so it was crucial that the indicators chosen to measure the Project objectives express the expectations of Pilot stakeholders while remaining sensitive to practical concerns associated with conducting the research. The terms of reference for the evaluation provided the basis for developing the evaluation framework (Centre for Independent Living in Toronto 1994). The Evaluation Sub-Committee met with representatives of The Roeher Institute to review this document in relation to the design of the Project. These discussions allowed us to refine further the evaluation criteria, group these criteria under the objectives set for the Project, and propose indicators that reflect independent living goals. Appendix #2 outlines the relationship between the objectives, evaluation criteria, indicators and data sources drawn from the final version of the evaluation framework approved by the steering committee. One Evaluation Sub-Committee member with a disability indicated to the evaluation team that the development of concrete measures of independent living goals, such as empowerment, represented a very significant legacy of the research.

## **Overview of ethical issues, procedures for obtaining consent and protection of respondent confidentiality**

A document prepared by The Roeher Institute concerning these matters was discussed with the Evaluation Sub-Committee and other members of the Steering Committee. It outlined a plan for the ethical collection and analysis of the data pertaining to this Project, with provisions for protecting confidentiality of information collected from respondents.

## Surveys of self-managers

In total, seventy-eight people began participating in the Pilot in the winter and spring months of 1995. These self-managers were surveyed twice, using two distinct mailed questionnaires with some variables included in both instruments in order to assess changes over time. An additional twenty-four were selected in the spring of 1996. These self-managers were surveyed once by telephone.

A letter from the Executive Director of The Roeher Institute, a two-page overview of the evaluation and a stamped, addressed envelope in which to return the completed survey to The Roeher Institute accompanied each mailed questionnaire. The letter invited self-managers to complete the survey and it indicated that only members of the evaluation team would review the surveys and that identifying information would not be shared with those affiliated with the Pilot or anyone else without express permission. The letter assured self-managers that the final report would not identify respondents unless particular individuals agreed otherwise. A similar letter from the Executive Director of The Roeher Institute and the two-page overview of the evaluation was mailed to all twenty-four participants selected in 1996.

The mailed surveys repeated The Roeher Institute's commitment to maintaining confidentiality, including our plans to dispose of the surveys upon publication of this report. The first page of the mailed surveys also indicated that self-managers could request a telephone interview or a copy of the survey in an alternate format. The interviewer reviewed these provisions before proceeding with the telephone interviews.

The survey questions were determined in relation to the evaluation framework. The identification of critical factors through other aspects of the evaluation and discussions with the Evaluation Sub-Committee and other Steering Committee members refined the design of these instruments.

### *First survey of self-managers selected in 1995*

In order to be mailed a copy of the first survey, at least two months had to have passed since the self-managers had been notified that they had been accepted as participants in the Pilot. In addition to undergoing a detailed review by the Evaluation Sub-Committee, the first five accepted applicants field tested the first survey. They were mailed a copy in April 1995. On the basis of feedback from the test group, the instrument was modified slightly. Surveys were mailed to the remaining seventy-three in September through December 1995.

By 2 February 1996, fifty-two self-managers had responded. A reminder letter was sent to each self-manager during the first week of February. An additional six surveys were received after 2 February, bringing the total number of responses up to fifty-eight for a

response rate of 74%. The typical response rate for mail-in surveys is 50%, and a response rate in Canada of over 68% is generally considered excellent (Jackson 1988).

Two self-managers responded anonymously, six completed the survey via telephone, and two reported that they had lost their surveys and so new instruments were mailed.

#### *Follow-up survey of the self-managers selected in 1995*

The second of two questionnaires designed to be self-administered were mailed to the initial group of seventy-eight self-managers in June 1996. A reminder letter was sent the last week of August 1996 and a second reminder letter was sent the third week of September 1996. In total, sixty-three surveys were received for a response rate of 81%.

Two surveys were returned anonymously, six responded by telephone. Two individuals requested and returned diskette copies of the survey.

#### *Representativeness of respondents selected in 1995*

Since not all participants selected in 1995 responded to the first and follow-up surveys mailed to them, the demographic profile for the group as whole at the outset of the Project was compared with the profiles of respondents to these surveys. The information on the group as a whole was drawn from the applications.

As shown in the table below, those who responded to the first and follow-up surveys are representative of the group selected in 1995. In other words, the sample is not skewed.

Appendix 1. Figure 1. Representativeness of Respondents Selected in 1995

Variable	Test	First Survey	Follow-up Survey
age	ANOVA	n.s.	n.s.
gender	chi-square	n.s.	n.s.
region	chi-square	n.s.	n.s.
rural/urban	chi-square	n.s.	n.s.
self-management score	ANOVA	n.s.	n.s.
lived alone/with others	chi-square	n.s.	n.s.
number of sources for paid attendant services	ANOVA	n.s.	n.s.

- Those who responded anonymously were excluded from this analysis, as their demographic characteristics were mostly unknown.
- The region variable was recoded to Central East (where fifty-two out of 102 participants reside) and others, since the numbers in some regions were too low to permit chi-square value to be calculated.

*Survey of the self-managers who began participating in 1996*

The twenty-four self-managers who were selected in 1996 were contacted for a telephone interview in November 1996. A telephone interview was not suitable for two self-managers. They were sent a copy by mail, and both returned their completed questionnaires. The others were interviewed between 15 November and 10 December 1996. All telephone interviews were conducted by the same researcher. The response rate for this group was therefore 100%.

**Survey of attendant workers**

Two packages were sent with a cover letter from the Executive Director of The Roeher Institute to each self-manager: The letter asked the self-manager to give the packages to the two attendants who work the most hours for him or her, and it told the self-manager that the packages contained:

- a brief description of the Pilot Project prepared by the Project Administration;
- a letter from the Executive Director of The Roeher Institute inviting attendants to participate and outlining The Roeher Institute's commitment to maintaining confidentiality;
- an overview of the evaluation, identical to the one distributed to self-managers;

- a survey to be completed by the attendant;
- a stamped, addressed envelope in which to return the completed survey directly to The Roeher Institute.

The letter also asked self-managers to tell attendants that self-managers would not have any access to completed surveys.

The evaluation team and members of the Evaluation Sub-Committee determined that this method of distributing the surveys was most appropriate. Asking self-managers to provide the evaluation team with the names and addresses of their attendants was the other alternative considered. However, as the letter to self-managers explained, this option could have placed self-managers in a position of violating the confidentiality of those working for them.

Given that the first survey of self-managers who began participating in 1995 revealed that many self-managers have five or more attendants on their payroll, it was not feasible to survey each and every attendant. The decision to sample the two attendants who work the most hours was based on sampling those with the greatest stake in the Pilot, and therefore those who could provide the most meaningful data and who also seemed the most likely to complete the survey.

In addition to the assurances provided in the letters to self-managers and to attendants, the survey itself explicitly indicated that only the researchers would review the surveys and that no one else, including the self-manager who gave the attendant the survey, would have access to the completed questionnaires.

In March 1996, the packages were mailed to self-managers who began participating in 1995. That is, 156 surveys were distributed.

Four attendants did not name the self-manager who gave them the survey, and two of these attendants did not provide their own names. Two self-managers reported the packages lost, and so new sets were mailed.

An attendant reported that one self-manager did not distribute the surveys. Three self-managers returned one of the packages sent to them, and one returned both. Two of these self-managers employ only one attendant. The other packages were returned because one or both of the main attendants had not yet worked for two months.

In addition to those who returned one of the packages sent to them, twenty-five self-managers indicated in their second survey that only one attendant works ten or more hours per week. As well, twenty-three of the self-managers selected in 1995 whose follow-up surveys arrived at The Roeher Institute by the end of August indicated that turnover had occurred since January. Presuming that half of this turnover occurred

after March and taking into account the other factors outlined above, the estimated sampling frame is 113. Given that The Roeher Institute received seventy-seven completed questionnaires, the estimated response rate is 68%.

The job diagnostic measure developed by Lee, Mueller and Miller (Lee, Mueller, and Miller 1981) was modified slightly in order to make sense within the employer-employee relationship particular to the Pilot. Neysmith and Nichols used this instrument to measure job satisfaction with analogous groups of workers in Ontario and Quebec (Neysmith and Nichols 1994), rendering possible comparisons between attendants employed by self-managers and home-help agency staff. Given that the wording of some of the variables was altered slightly to make sense within the context of the Pilot, the index was tested for:

- *variability* (scores ranged from 26 to the maximum, 102);
- *internal consistency* (probability scores of 0.000 on all one-way ANOVAs between index and component variables); and
- *reliability* (Cronbach's alpha score of 0.936).

#### **Data from the application**

The application forms provided a valuable source of information on the demographic profile of participants and their pre-Pilot living and attendant service arrangements. A CILT staff member entered this information into a data base to support its activities as Project Administration. Data on selected variables were supplied to the evaluation team upon request and recoded for analysis.

#### **Comparison group drawn from the Health and Activity Limitations Survey (1991)**

A sub-sample of the Health and Activity Limitations Survey (HALS) conducted by Statistics Canada in 1991 was constructed in order to compare selected applicants with others who appear to meet the eligibility criteria. All residents of Canada aged 15 and over who did not live in an institution and who identified themselves as having a disability in the long census form were interviewed in person for this survey.

The following variables from HALS approximate the types of assistance provided by attendants under this Pilot:

- receives or has unmet needs for assistance in getting in or out of bed
- receives or has unmet needs for assistance in personal care (examples given were washing, grooming, dressing and eating)
- uses specialized devices or equipment for breathing

- receives or has unmet needs for assistance in meal preparation
- receives or has unmet needs for assistance in everyday housework
- receives or has unmet needs for assistance in essential communication

In 1991, approximately 1.2 million people in Canada with a long-term physical disability required at least one of these services. Over half a million of this group lived in Ontario.

In order to be eligible for selection for this Pilot Project, applicants had to require assistance with at least two of the services above and at least one of the following: getting in/out of bed or personal care. In 1991, over half a million people in Canada with a long-term physical disability met these criteria.

The questionnaire used for HALS 1991 did not contain appropriate proxy variables for catheterization, emptying or changing a leg bag, using the toilet, urination or bowel routines. Therefore, these figures should be considered conservative in estimating the number of people who require attendant services and who would meet the eligibility criteria for attendant services under this Pilot Project.

In addition to requiring assistance as stipulated above, applicants had to live in Ontario and demonstrate the capacity for self-direction and self-management. Therefore, for comparison purposes, a subset was constructed using HALS that consisted of those residing in Ontario at the time of the survey and who:

- experienced no ongoing difficulties remembering or learning;
- experienced no difficulties in solving day-to-day problems;
- experienced no difficulties following steps; and
- managed personal finances independently, or if they shared this responsibility with someone else, did not do so because of their disability.

Approximately 45,000 people in Ontario met these additional criteria concerning self-direction and self-management.

### **Quantitative data coding and analysis**

The MicroCase Analysis System, version 3.5, was used for coding the data. This software package was also used to perform the quantitative data analysis.

The survey of attendant workers asked how many hours, on average, respondents worked per week for the self-manager who gave them the survey. A number of attendants indicated a range of hours, for example "15-20." In these cases, the mean value of the range indicated was coded as the response.

### **Focus group with selection panellists**

A focus group was convened with the selection panellists who interviewed applicants in the region that had the most applications. The session was held in July 1995. Some participants had also been part of selection panels in other regions, and some also participated in selection panels convened in 1996.

### **Observation of a selection panel interview**

One of the members of the research team attended a selection panel interview as an observer. This interview was particularly significant, given that the interviewee was one of eight non-selected applicants who requested a review of the decision and one of three granted an interview as a result of the review process. Verbal consent was obtained prior to the commencement of the interview, followed up with a letter from the Executive Director of The Roeher Institute confirming consent.

### **Participant-observation at a workshop held for ILRC staff**

One of the members of the research team gave a brief presentation on the evaluation, together with one of the Ministry of Health representatives on the Evaluation Sub-Committee, and observed during the rest of the day-long event hosted by CILT. Verbal consent to observe the workshop was obtained from participants.

### **Participant-observation at a regional workshop of self-managers**

One of the members of the research team gave a brief presentation on the evaluation, and observed during the rest of the evening-long event. A verbal consent process was employed, and participants were invited to call The Roeher Institute if they did not want some or all of their remarks to be used as data in the evaluation. None of the participants did so.

### **Participant-observation during meetings of the Steering Committee**

At least one member of the evaluation team attended all Steering Committee meetings throughout 1995 and 1996, which took place approximately every three months. Members of the evaluation team also attended one meeting of the Steering Committee held in 1994. These meetings were a valuable forum for gathering information about the Project, and, in particular, understanding the nature and extent of the partnership forged between government and consumers through the development and implementation of this Pilot Project.

## **Interviews with self-managers**

Besides the telephone interviews conducted with self-managers selected in 1996 and with self-managers selected in 1995 upon request, semi-structured interviews were conducted with a sample of the self-managers selected in 1995, stratified by region and gender. These interviews were conducted in December 1996 and during the first week of January 1997. In total, seventeen self-managers were interviewed in this manner. Of these, seven reside in the Central East region. At least one individual from each of the regions was interviewed. Four declined to be interviewed.

## **Interviews with other key informants**

A number of key informants besides the self-managers were interviewed. Most of these interviews took place in December 1996. In total, fifteen individuals were interviewed.

## **Coding of interview data and comments from the surveys**

The interviewer prepared a summary of each interview, including illustrative quotes, according to the following headings:

- Consumer-driven partnership
- Participation in the Pilot Project
- Flexibility, choice and control over attendant services
- Social and economic participation
- Employer-employee relationships
- Utilization and effectiveness of supportive resources
- Responsiveness of the Pilot Project
- Cost-effectiveness
- Other

A Roeher Institute researcher sorted the information under each heading and also entered the names of those interviewed, the names of the interviewer, the role of the respondent (for example, self-manager) and the date of the interview in a data base set up using the Lotus Approach 3.0 software package. Comments made during telephone interviews or provided in written form on returned surveys were coded according to the same schema. The data was then analyzed by category and respondent sub-group.

## **Review of public and internal documents pertaining to the Pilot Project**

Members of the Evaluation Sub-Committee were asked to forward documents that they considered relevant. Certain documents were specifically requested from individuals interviewed during the course of this Project and from the Pilot Administration. These documents were coded according to a list of thirty key words derived from the

evaluation framework and preliminary data analysis and entered into a bibliographic data base set up using the Endnote 2.0 software package.

### **Review of models and results from other individualized funding initiatives**

A critical review of models and results from other individualized funding initiatives was undertaken during the course of the evaluation. This review was produced as a separate document.

### **Cost-effectiveness analysis**

Meetings with the Project Administration and Evaluation Sub-Committee were held in order to clarify the questions that would guide the cost-effectiveness analysis, to determine the assumptions upon which the analysis would be made, to identify data sources to be drawn upon, and to develop a critical path for conducting the analysis.

The research questions that guided the cost-effectiveness analysis were:

- What are the net benefits per dollar spent in the supply-side system (SSLU and Outreach) compared to the self-managed direct funding system?
- What savings are associated with self-managed direct funding by enabling attendants to perform routine services such as catheterization, rather than requiring nurses or other health care professionals to perform these tasks?
- What savings are associated with self-managed direct funding through decreased utilization of health care facilities?

The methods used to calculate unit costs for the Pilot, the SSLU system and the Outreach system are described in the main body of the text, as are the methods used to calculate potential savings from more efficient use of health care facilities and reduced reliance on Home Care. Below, the methods used to calculate net benefits are described in detail.

In order to determine net benefits, variables indicating both benefits and features of the Pilot that participants might experience as drawbacks were included in the surveys of self-managers. The benefits were drawn from the Project objectives concerning outcomes for consumers as articulated in the evaluation framework; for example, greater choice in attendant services and greater choice overall for participants were two of the aims of the Pilot. The elements of the Pilot that some participants might experience as drawbacks were identified in consultation with the Evaluation Sub-Committee; for example, some participants might find legal liability as an employer to be a drawback of the program.

In the first survey of self-managers selected in 1995, respondents were asked to indicate whether or not they had experienced selected Project objectives as a result of the Project; that is, the available responses were "yes" and "no." In the follow-up survey of these self-managers, respondents were asked if they had experienced an increase or improvement in these selected Project objectives, if they had experienced a decrease or worsening in these areas, or if they had experienced no change in these areas since January 1996. This date was chosen because few self-managers had received the first survey in December 1995 and because the beginning of a new year is a standard reference point. Finally, some self-managers did not complete the first survey, and so asking them to report upon any changes since the first survey would not be meaningful. self-managers selected in 1996 were asked if they had experienced a decrease or worsening in these areas, or if they had experienced no change in these areas as a result of their participation in the Pilot.

In the first survey of self-managers selected in 1995, respondents were asked to indicate whether or not they had experienced selected features of the Pilot as drawbacks; that is, the available responses were "yes" and "no." In the follow-up survey of these self-managers, respondents were asked if they had experienced these features as drawbacks since January 1996, or if this element did not apply to them; that is, the available responses were "yes," "no" and "not applicable." Similarly, self-managers selected in 1996 were asked if they had experienced these features as drawbacks, or if this element did not apply to them.

Four indices were constructed to measure benefits and drawbacks: B1, D1, B2, D2. In constructing these indices, the affirmative scores were summed. Those who did not respond to a given question were assigned a score of zero. A number of respondents only checked the affirmative responses, leaving the other items blank.

The scores on these indices demonstrated considerable variance across cases on each of these measures, a desired quality in any index. In addition, they are internally consistent, as indicated by the tables below.

Appendix 1. Figure 2.

Internal Consistency Tests for Benefit Components of Net Benefit Measures

ANOVAs (B1 and B2 cf. component variables)	B1 (p values)	B2 (p values)
choice in attd svcs	0.000	0.000
choice overall	0.000	0.000
control over attd svcs	0.000	0.000
control overall	0.000	0.000
management skills	0.001	0.000
independence	0.000	0.000
personal comfort	0.000	0.000
social, leisure activities	0.000	0.000
relations with family, friends	0.000	0.000
relations with intimate partner	0.000	0.000
participation in education	0.033	0.045
employment opportunities	0.000	0.000
ability to travel	0.000	0.000
working relationships with attendants	0.003	0.001
access to health-related svcs	0.004	0.009
difference in health status	0.050	0.000

• The scores on working relationships with attendants, access to health-related services, and difference in health status for participants selected in 1996 were included in B1, while the scores on these variables for participants selected in 1995 were included only in B2.

Appendix 1. Figure 3.

Internal Consistency Tests for Drawback Components of Net Benefit Measures

ANOVAs (D1 and D2 cf. component variables)	D1 (p values)	D2 (p values)
sole responsibility for attd svcs	0.000	0.001
legal liability	0.000	0.000
book-keeping	0.000	0.000
personnel management	0.000	0.000
invasion of privacy	0.000	0.004
conflicts with attd wkrs	0.000	0.000
changing attd wkrs	0.000	0.000
having to move	0.000	0.124

Only one index (D2) is not significantly associated with all of its constituent variables at the 0.05 level, as the "having to move" variable is not statistically significant. This result may be expected, given that those who had to move as a result of the Pilot (those

residing in an SSLU prior to the Pilot) and who may have been reluctant to do so would have changed housing arrangements shortly after learning of their acceptance.

Another means of testing reliability is through the split-halves test. This test involves creating two sub-scales from the component variables of an index; in this case, benefits (B1 and B2), drawbacks (D1 and D2) and net benefit (NB). The Cronbach's alpha score of 0.928 on the split-halves test indicates that the composite measure, net benefit, is very reliable. Generally, a Cronbach's alpha score of 0.7 or greater between the sub-scales indicates that the overall scale may be accepted as a reliable measure. Each of the component indices as well as the composite measure, net benefit, exceeds this threshold.

Appendix 1. Figure 4.  
 Split Halves Reliability Tests on Net Benefit Index and Its Components

	Cronbach's alpha	p value
B1	0.935	>0.01
D1	0.869	>0.01
B2	0.926	>0.01
D2	0.732	>0.01
Net Benefit	0.928	>0.01

- Derived from calculating correlations between indices' split-halves using list-wise deletion (1-tailed test)
- B1: B1a (choice in attendant services, control over attendant services, management skills, independence, social, leisure activities, improved access to medical and other health-related services) cf. B1b (choice overall, control overall, flexibility, personal comfort, relations with family, friends, relations with intimate partner, participation in education, employment opportunities, ability to travel, improved working relations with attendants)
- D1: D1a (sole responsibility for attd svcs, legal liability, book-keeping, personnel management) cf. D1b (invasion of privacy, conflicts with attd wkrs, changing attd wkrs, having to move)
- B2: B2a (choice in attendant services, control over attendant services, management skills, independence, social, leisure activities, working relationships with attendants, access to health-related services) cf. B2b (choice overall, control overall, personal comfort, relations with family, friends, relations with intimate partner, participation in education, employment opportunities, travel, difference in health status)
- D2: D2a (sole responsibility for attd svcs, legal liability, book-keeping, personnel management) cf. D2b (invasion of privacy, conflicts with attd wkrs, changing attd wkrs, having to move)
- Net Benefit: (B1a+B2a) - (D1a+D2a) cf. (B1b+B2b) - (D1b+D2b)

Two versions of the benefit and drawback indices (B1, B2, D1 and D2) were used for the purpose of calculating net benefits (NB):

1. In the first version, those in the first group of seventy-eight who did not return one or both surveys sent to them were assigned a *score of zero*. Those who were selected in 1996, and therefore only surveyed once, were also assigned a score of zero for the measures of benefits and drawbacks enumerated in the follow-up survey (B2 and D2).
2. In the second version, the *mean score* on these indices was assigned to those in the first group who did not return the first survey and/or the follow-up survey. The means score was also assigned to those selected in 1996.

The first net benefit score ( $NB_0$ ) is the more conservative estimate of net benefits. This score is derived from summing benefits enumerated in the first survey of self-managers and the follow-up survey of self-managers, and then subtracting the sum of the drawbacks enumerated in these surveys. Its formula is represented below:

$$NB_0 = (B1_0+B2_0) - (D1_0 + D2_0)$$

The scores for  $NB_0$  are listed in the main body of the text in the cost-effectiveness section.

The second net benefit score ( $NB_M$ ) makes two assumptions:

- that those selected in 1995 who did not return one or both surveys experienced, on average, the same number of benefits and drawbacks as those who did;

and

- that those selected in 1996 would experience, on average, the same number of benefits and drawbacks after approximately one year of self-managing as those selected in 1995 who returned the follow-up survey.

Its formula is represented below:

$$NB_M = (B1_M+B2_M) - (D1_M + D2_M)$$

This measure was calculated by assigning the mean values on B1 and D1 to those selected in 1995 who did not return the first survey sent to them, assigning the mean values on B2 and D2 to those selected in 1995 who did not return the follow-up survey sent to them, and assigning the mean values on B2 and D2 to those selected in 1996. The scores for  $NB_M$  are listed in the main body of the text in the cost-effectiveness section.

The mean values on  $B1_0$ ,  $B2_0$ ,  $D1_0$  and  $D2_0$  are shown in the table below. The table contains both the value to two decimal places and the value rounded to the nearest integer. In calculating  $B1_M$ ,  $B2_M$ ,  $D1_M$ ,  $D2_M$  and ultimately  $NB_M$ , the rounded figures were used.

Appendix 1. Figure 5.  
 Mean Values on Components of Net Benefit Index (NB<sub>0</sub>)

Component Index	Mean Value
B1 <sub>0</sub>	7 (6.54)
B2 <sub>0</sub>	4 (4.36)
D1 <sub>0</sub>	1 (0.78)
D2 <sub>0</sub>	0 (0.38)

The wording of the questions in the surveys made it possible to compare the Pilot Project with SSLU and Outreach attendant service programs in terms of net benefits, for respondents were asked if they had experienced any of listed benefits or drawbacks *as a result of the program*. That is, they were asked to compare their present circumstances with their circumstances prior to beginning the Pilot program. While not all participants received services from Outreach or in a SSLU prior to becoming self-managers, all met the eligibility criteria for one or both of these programs.

In order to analyze the net benefits experienced by selected applicants in relation to unit costs, a value of one was assigned as a net benefit score to the SSLU and Outreach programs. In order to make a comparison of cost-effectiveness ratios mathematically possible, a value other than zero had to be assigned to the net benefit score. By assigning a value of one rather than a decimal value, a conservative estimate of net benefit is calculated. In effect, one additional drawback with the Pilot is assumed for each self-manager. A number of self-managers were not receiving attendant services through Outreach or an SSLU prior to the Pilot, although all met the eligibility criteria for one or both programs. Therefore, caution must be exercised in comparing the cost-benefit ratios for those who did not receive these services with the cost-benefit ratios calculated for these services. In the cost-effectiveness section of the report, the scores for those who were consumers of Outreach and SSLU services are specified, as are the scores of those who would best be considered Outreach and SSLU candidates.

Comparisons can *only* be made with and among those who participated in the Pilot Project. The net benefits and the unit costs calculated for the Pilot Project apply *exclusively* to this initiative. There is no empirical basis for assuming that other people with disabilities presently served by Outreach or in SSLUs could have participated in the Pilot Project at the same unit cost or with the same net benefit scores.

## Appendix #2: Evaluation Framework

The *overall purpose of the evaluation* is:

**to evaluate the capacity of the direct funding model implemented in this Pilot Project to address, in a cost-effective manner, consumer demands for flexibility, choice and control over attendant services.**

Accordingly, The Roeher Institute was engaged:

- a) to evaluate the "consumer-driven" partnership with the Ministry of Health throughout all phases and aspects of the Self-Managed Direct Funding Pilot Project;
- b) to evaluate the extent to which the Pilot Project addresses consumer demands for flexibility, choice and control over attendant services;
- c) to assess the satisfaction of self-managers with the Pilot Project related to their social and economic integration, including work, family life, community activities, freedom of movement, and increased levels of skill, confidence and self-determination;
- d) to evaluate the employer-employee relationships and the impact/implications for workers;
- e) to compare the costs, benefits and equity of self-managed attendant service vis-a-vis services in managed/delivered models (e.g., SSLUs, Outreach);
- f) to assess the utilization and effectiveness of supportive resources;
- g) to determine the responsiveness of the direct funding Pilot Project to variance in self-managers' circumstances and needs;
- h) to identify factors and trends related to the break-down of service arrangements, should this occur;
- i) to evaluate the process and criteria for terminating of individuals' direct funding arrangements during the course of the Pilot Project
- j) to determine appropriate procedures to ensure financial accountability mechanisms
- k) to identify barriers to participation in the direct funding Pilot Project

The Evaluation Sub-Committee of the Pilot Steering Committee and representatives of The Roeher Institute met on a number of occasions to review the Terms of Reference in relation to the design of the Project. These discussions have allowed The Roeher Institute to further refine the evaluation criteria, group these criteria under the objectives (a-k above), and propose indicators that reflect independent living goals. The relationship between the evaluation criteria, indicators and data sources are laid out in the pages that follow.

**a) to evaluate the "consumer-driven" partnership with the Ministry of Health throughout all phases and aspects of the Self-Managed Direct Funding Pilot Project**

Evaluative Criteria	Indicators	Data Sources
<ul style="list-style-type: none"> <li>stakeholders demonstrate commitment to promoting independent living in the community</li> </ul>	<ul style="list-style-type: none"> <li>Project stakeholders (self-managers, resource organizations, Project administration, government representatives) share a commitment to the goals of flexibility, choice and control</li> <li>decisions taken by committees, Project administration, selection panels and resource organizations respect the goals and mandate of the Pilot Project</li> <li>policy guidelines and contracts promote flexibility, choice and control in the management of service provision</li> </ul>	<ul style="list-style-type: none"> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>review of documents and records</li> </ul>
<ul style="list-style-type: none"> <li>Pilot Project responds to requirements (e.g., regional characteristics) of resource organizations, committees and selection panels</li> </ul>	<ul style="list-style-type: none"> <li>Project administration able to provide effective support to resource organizations, committee, selection panels</li> <li>selection panels have guidelines as to the desired consumer mix (e.g., consumer perspective, gender, ethno-racial background, regions)</li> <li>administrative procedures and adequate funding in place to enable Project administration to carry out its role in the Project</li> </ul>	<ul style="list-style-type: none"> <li>interviews with key informants other than self-managers</li> <li>review of documents and records</li> </ul>

<ul style="list-style-type: none"> <li>committee processes enable all stakeholders to participate in consensual decision-making</li> </ul>	<ul style="list-style-type: none"> <li>stakeholders assign importance to consumer leadership in the design, planning and implementation of the Pilot Project</li> <li>stakeholders identify processes and outcomes that do or do not reflect the vision of a consumer-driven process</li> <li>stakeholders perceive that relations between and among themselves are characterized by cooperation, mutual respect and collaborative problem-solving</li> </ul>	<ul style="list-style-type: none"> <li>interviews with key informants other than self-managers</li> <li>review of documents and records</li> </ul>
<ul style="list-style-type: none"> <li>communication channels (e.g., written reports, informal consultation) between government and Project administration enable mutual accountability and effective Project implementation</li> </ul>	<ul style="list-style-type: none"> <li>reporting relationships among stakeholders characterized by timely and accurate exchange of information</li> <li>mechanisms in place to identify and resolve conflict between and among stakeholders</li> <li>communication activities and strategies around Pilot Project meet the requirements of all stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>interviews with key informants other than self-managers</li> <li>review of documents and records</li> </ul>

**b) to evaluate the extent to which the Pilot Project addresses consumer demands for flexibility, choice and control over attendant services**

Evaluative Criteria	Indicators	Data Sources
<ul style="list-style-type: none"> <li>self-managers report increased flexibility, choice and control over attendant services, and in their lives more generally</li> </ul>	<ul style="list-style-type: none"> <li>the Pilot Project enables self-managers to exercise increased choice, flexibility and control in making attendant service arrangements</li> <li>the Pilot Project enables self-managers to choose attendants</li> <li>self-managers report satisfaction with attendant service arrangements made under the Pilot Project</li> <li>the Pilot Project facilitates the achievement of personal goals</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> </ul>

<ul style="list-style-type: none"> <li>• communication (e.g., written reports, informal consultation) between government and Project administration reflects and includes self-managers' feedback and issues</li> </ul>	<ul style="list-style-type: none"> <li>• Project administration actively seeks feedback from self-managers, and shares the content of this feedback in non-identifying ways with members of the steering committee</li> <li>• government representatives perceive the information shared about self-manager experiences under the Pilot Project to be accurate, and the monitoring process to be respectful</li> <li>• Project administration perceives government accountability expectations to be consistent with the principle of consumer responsibility and control</li> </ul>	<ul style="list-style-type: none"> <li>• survey of self-managers</li> <li>• interviews with self-managers</li> <li>• interviews with key informants other than self-managers</li> <li>• review of documents and records</li> </ul>
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**c) to assess the satisfaction of self-managers with the Pilot Project in relation to their social and economic integration, including work, family life, community activities, freedom of movement, and increased levels of skill, confidence and self-determination**

Evaluative Criteria	Indicators	Data Sources
<ul style="list-style-type: none"> <li>• the Pilot Project empowers self-managers to play an active role in families, communities and society as a whole</li> </ul>	<ul style="list-style-type: none"> <li>• self-managers report increased control and choice, resulting in self-growth and increased social and economic participation</li> <li>• self-managers report that they have increased social and economic opportunities</li> <li>• self-managers report that they are better able to plan for the future</li> </ul>	<ul style="list-style-type: none"> <li>• survey of self-managers</li> <li>• interviews with self-managers</li> <li>• review of documents and records</li> </ul>

<b>d) to evaluate the employer-employee relationships and the impact/implications for workers</b>		
<b>Evaluative Criteria</b>	<b>Indicators</b>	<b>Data Sources</b>
<ul style="list-style-type: none"> <li>self-managers effectively carry out their role as an employer</li> </ul>	<ul style="list-style-type: none"> <li>self-managers keep required records and adhere to required reporting mechanisms</li> <li>consistent with the principles of consumer responsibility and control, monitoring and tracking mechanisms find that self-managers are adhering to employment-related laws and regulations</li> <li>effective procedures and processes in place for recruiting, hiring, training, scheduling, paying, evaluating and dismissing attendants</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>survey of attendant workers</li> <li>review of documents and records</li> </ul>

<ul style="list-style-type: none"> <li>• self-managers are enabled to effectively carry out their role as an employer</li> </ul>	<ul style="list-style-type: none"> <li>• the Pilot Project provides participating self-managers with information about employment-related laws and regulations</li> <li>• as required or requested, Project administration and/or resource organizations assist self-managers with putting these procedures and processes in place</li> </ul>	<ul style="list-style-type: none"> <li>• survey of self-managers</li> <li>• interviews with self-managers</li> <li>• interviews with key informants other than self-managers</li> <li>• survey of attendant workers</li> <li>• review of documents and records</li> </ul>
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<ul style="list-style-type: none"> <li>the employer-employee relationship is positive from both self-managers' and attendant workers' perspectives</li> </ul>	<ul style="list-style-type: none"> <li>self-managers enjoy an improved life situation as a result of increased responsibility and control in attendant service arrangements</li> <li>the Pilot Project enables self-managers to offer quality work experiences to attendants, including the provision of adequate wages and benefits</li> <li>self-managers, with the assistance of resource organizations and/or Project administration where requested or required, put effective problem resolution mechanisms in place to deal with potential or actual employer-employee conflicts</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>survey of attendant workers</li> <li>review of documents and records</li> </ul>
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<b>e) to compare the costs, benefits and equity of self-managed attendant service vis-a-vis services in managed/delivered models (e.g., SSLUs, Outreach)</b>		
<b>Evaluative Criteria</b>	<b>Indicators</b>	<b>Data Sources</b>
<ul style="list-style-type: none"> <li>information strategy, application, selection and review procedures and processes meet all stakeholders' requirements</li> </ul>	<ul style="list-style-type: none"> <li>application, selection and review procedures and processes are designed and implemented so that consumers can make informed choices about participating in the Project, planning for the transition to direct funding, and seeking a review of selection and service plan decisions</li> <li>self-managers participating in the Pilot Project represent a consumer mix</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>review of documents and records</li> </ul>
<ul style="list-style-type: none"> <li>information strategy, application, selection and review procedures and processes meet standards of fairness</li> </ul>	<ul style="list-style-type: none"> <li>the selection and eligibility criteria (e.g., self-management capacity, consumer mix) provide a broad enough base from which to evaluate the viability of the self-managed direct funding Pilot Project, while providing a coherent and fair rationale for selecting some consumers and not others</li> <li>Project administration informs a broad consumer base (assisted by resource organizations) about the Project</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>review of documents and records</li> </ul>

<ul style="list-style-type: none"> <li>the Pilot Project represents an service provision model that facilitates independent living in the community</li> </ul>	<ul style="list-style-type: none"> <li>the Pilot Project enables self-managers to achieve independent living goals</li> <li>the Pilot Project helps Independent Living Resource Centres fulfil their mandate</li> <li>self-managers report increased control and choice, resulting in self-growth and increased social and economic participation</li> <li>the Project strengthens the capacity of Project administration and resource organizations to promote innovative approaches that facilitate independent living in the community</li> <li>the Pilot Project provides attendant workers with working conditions that are equitable, if not superior, to managed service arrangements</li> <li>the Pilot Project facilitates systemic responsiveness in private and public sectors (e.g., education, employment) to self-manager and community requirements</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>survey of attendant workers</li> <li>review of documents and records</li> </ul>
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<ul style="list-style-type: none"> <li>• funding and administrative mechanisms meet the requirements of all stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>• funding levels for self-managers are adequate, permitting them to hire and retain staff to perform the attendant service duties that they require</li> <li>• administrative mechanisms ensure mutual accountability, while not straining the capacity of Project administration, resource organizations or self-managers</li> <li>• costs of the Pilot Project compare favourably to managed/delivered models (costs for individuals, hours of service, aggregate costs)</li> <li>• funding for resource organizations and Project administration permit them to fulfil their responsibilities under the Project</li> </ul>	<ul style="list-style-type: none"> <li>• survey of self-managers</li> <li>• interviews with self-managers</li> <li>• interviews with key informants other than self-managers</li> <li>• survey of attendant workers</li> <li>• review of documents and records (includes costing data on other delivery systems)</li> </ul>
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**f) to assess the utilization and effectiveness of supportive resources**

Evaluative Criteria	Indicators	Data Sources
<ul style="list-style-type: none"> <li>Project administration promotes information-sharing within the ILC network, with attendant workers, with government and among self-managers, so that stakeholders learn from one another how to implement direct funding so that it best serves self-managers</li> </ul>	<ul style="list-style-type: none"> <li>Project administration provides resource organizations with support (resource materials/methods, orientation, coordination and ongoing liaison) to enable them to carry out their role in the Project</li> <li>Project administration provides attendants with referrals, plays a facilitative role viz. issues in relations between attendants and self-managers, and promotes networking among attendants</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>survey of attendant workers</li> <li>review of documents and records</li> </ul>

<ul style="list-style-type: none"> <li>resource organizations promote information-sharing within the ILC network, with attendant workers, with government and among self-managers, so that stakeholders learn from one another how to implement direct funding so that it best serves self-managers</li> </ul>	<ul style="list-style-type: none"> <li>resource organizations assist self-managers individually (assistance upon request) and collectively (peer networking, workshops, etc.) for enhanced self-management capacity</li> <li>resource organizations provide attendants with referrals, play a facilitative role viz. relations between attendants and self-managers, and promote networking among attendants</li> <li>resource organizations share information about dilemmas and innovations with each other and with Project administration</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>survey of attendant workers</li> <li>review of documents and records</li> </ul>
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<ul style="list-style-type: none"> <li>formal and informal support resources meet self-managers' requirements, resulting in enhanced capacity for self-management and participation in community life</li> </ul>	<ul style="list-style-type: none"> <li>information and referrals from resource organizations expose self-managers to a range of options, enabling self-managers to make informed choices and have greater access to community resources</li> <li>mutual support gained through networks of self-managers reduce isolation and promote peer learning</li> <li>Project administration works effectively with resource organizations to promote peer support</li> <li>resources prepared by Project administration meet self-managers' requirements</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>review of documents and records</li> </ul>
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<b>g) to determine the responsiveness of the direct funding Pilot Project to variance in self-managers' circumstances and needs</b>		
<b>Evaluative Criteria</b>	<b>Indicators</b>	<b>Data Sources</b>
<ul style="list-style-type: none"> <li>self-management of funds promotes flexible, responsive attendant services</li> </ul>	<ul style="list-style-type: none"> <li>Pilot Project effectively responds to changes in individual self-managers' requirements for attendant services (e.g., hours, duties)</li> <li>Pilot Project effectively responds to variance between individual self-managers' requirements for attendant services</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>survey of attendant workers</li> <li>review of documents and records</li> </ul>

<b>h) to identify factors and trends leading service arrangements to break down, should this occur</b>		
<b>Evaluative Criteria</b>	<b>Indicators</b>	<b>Data Sources</b>
<ul style="list-style-type: none"> <li>self-managers are supported by other stakeholders to respond in a timely and effective manner to breakdowns in service arrangements</li> </ul>	<ul style="list-style-type: none"> <li>Project administration and resource organizations work with self-managers to document causes of service breakdowns, take preventive measures, and formulate back-up plans</li> <li>government and Project administration seek to identify and address any systemic roots to these incidents</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>survey of attendant workers</li> <li>review of documents and records</li> </ul>

i) to evaluate the process and criteria for terminating direct funding arrangements		
Evaluative Criteria	Indicators	Data Sources
<ul style="list-style-type: none"> <li>Project administration and government develop guidelines and procedures for terminating direct funding</li> </ul>	<ul style="list-style-type: none"> <li>guidelines and procedures for terminating direct funding in the course of the Project balance respect for self-determination against mutual accountability among stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>review of documents and records</li> </ul>

j) to determine appropriate procedures to ensure financial accountability mechanisms		
Evaluative Criteria	Indicators	Data Sources
<ul style="list-style-type: none"> <li>• funding mechanisms to Project administration and resource organizations enable them to promote self-management while remaining accountable to each other and to government</li> </ul>	<ul style="list-style-type: none"> <li>• resource organizations' funding levels are adequate and funding flows are timely</li> <li>• Project administration enabled to effectively and sensitively carry out their role as transfer payment agency, including monitoring of self-managers' adherence to accountability guidelines</li> </ul>	<ul style="list-style-type: none"> <li>• interviews with key informants other than self-managers</li> <li>• review of documents and records</li> </ul>

<ul style="list-style-type: none"> <li>individual grant receipt and financial accounting procedures promote self-management and mutual accountability among stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>individual funding levels are adequate and funding flows are timely</li> <li>self-managers keep separate bank account to facilitate the transfer of funds, and to facilitate unobtrusive monitoring by Project administration</li> <li>self-managers direct the flow monies and other banking matters for the purpose of employing attendant workers under the Pilot Project</li> <li>self-managers keep accurate records and share these records with Project administration, upon request</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>survey of attendant workers</li> <li>review of documents and records</li> </ul>
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<b>k) to identify barriers to participation in the direct funding Pilot Project</b>		
<b>Evaluative Criteria</b>	<b>Indicators</b>	<b>Data Sources</b>
<ul style="list-style-type: none"> <li>the Pilot Project is designed and implemented to minimize barriers to participation in the Project</li> </ul>	<ul style="list-style-type: none"> <li>the pool of applicants reflect a representative mix of people with disabilities residing in Ontario</li> <li>the pool of self-managers that are selected to participate in the Project reflect a representative mix of the applicants</li> <li>the Project's eligibility and selection criteria are coherent and fair</li> <li>Steering Committee makes ongoing efforts to identify and, where possible, address barriers to participation</li> <li>Steering Committee and other stakeholders make efforts to identify prospective barriers, should the Pilot Project be continued or expanded</li> <li>Steering Committee and other stakeholders identify potential mechanisms in policy, design and implementation in order to address any prospective barriers identified</li> </ul>	<ul style="list-style-type: none"> <li>survey of self-managers</li> <li>interviews with self-managers</li> <li>interviews with key informants other than self-managers</li> <li>review of documents and records</li> </ul>

## Appendix # 3: History of the Direct Funding Pilot Project

According to those involved in promoting and administering this Project, the idea for a direct funding pilot project dates back at least ten years. By then, people involved in the independent living movement were aware of direct funding initiatives in Northern Europe and the United States. Disability activists were also aware that some people with disabilities were receiving direct funding, individualized according to need, through various mechanisms in Canada. For example, some war veterans' pensions provided for services and supports needed because of disabilities acquired during service in the armed forces. Some private insurance settlements included provision for attendant and other services. Worker's Compensation also used a direct funding approach. In 1988, individuals became eligible for direct funding under the *Vocational Rehabilitation of Disabled Persons Act*, which permits the Federal government to cover half of the eligible costs incurred by provincial and territorial governments (Roehrer Institute 1993a). Prior to 1984 in Ontario, Orders-in-Council had been passed to provide fifteen individuals with direct funding to cover the disability-related services required for them to live in the community.

The Outreach Attendant Services program came about in 1984 as a systemic means of responding to the demand for Orders-in-Council and providing an alternative to Supported Service Living Units (SSLUs).<sup>21</sup> It was originally intended that those in receipt of Orders-in-Council would switch to the Outreach system. However, the maximum number of hours provided by Outreach was 90,<sup>22</sup> an insufficient amount for some of the Order-in-Council recipients. Moreover, the locus of control in the Outreach and SSLU systems lay principally with the agency, not with the person who needed the services, even though applicants for these programs must demonstrate that they can direct their attendant services in order to be eligible. A number of consumers banded together to form the Attendant Care Action Coalition (ACAC). They wanted people who required attendant services to have full control over who provided these services, and when and where they were provided.

Meanwhile, data from the Health and Activity Limitations Survey, conducted in 1986 and 1991 by Statistics Canada, demonstrated that the need for attendant and other

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<sup>21</sup> SSLUs, which provide attendant services within clustered accessible housing units, were first created in 1975. Outreach differs from SSLUs in two ways. Firstly, it is not linked with a specific housing unit. To be eligible, applicants must have their housing in place. Secondly, while SSLUs provide scheduled and on-call services around the clock, Outreach services are restricted to scheduled routines and activities.

<sup>22</sup> The maximum number of hours for Outreach clients today is 120.

disability-related services exceeded the policy response. Combined with the policy shift towards deinstitutionalization, growing demand led to questions about how best to deliver disability-related services in the community. Consequently, provincial and Federal governments' interest in service brokerage and direct funding, individualized according to need, grew in the late 1980s and early 1990s.

Members of the independent living movement worked to bring the direct funding option to the attention of the Liberal and the NDP governments in Ontario. Along the way, their efforts included working with government officials to ensure that the new *Regulated Health Professions Act* made exemptions for procedures, such as catheterization, performed as part of an individual's "routine activities of living," which ensured a broad scope for attendant services (Ontario 1991, subsection 29{1}3 and subsection 30{5}e).

In response to consumer lobbying, the long-term care policy redirection introduced in 1991 contained a provision for a direct funding pilot project (Ontario Ministry of Community and Social Services, Ministry of Health, and Ministry of Citizenship 1991, p. 45). Representatives of ACAC, CILT and the Canadian Association of Independent Living Resource Centres (CAILC) wrote to the Minister of Health to express their interest in carrying out the Pilot. By then, the Independent Living Resource Centre in Winnipeg was already one year into a two-year self-managed attendant services pilot project. Said one of the respondents interviewed for this study,

*"At that point, we stopped asking the government to act. We realized that we were going to have to do the work. We were in a position to help them in a number of ways . . . We could take a problem off their hands."*

CILT had already managed a project with a budget in excess of \$1 million, it had served as a transfer payment agency with the provincial government, and its board of directors was very supportive of direct funding for attendant services. It was therefore in an ideal position to take a lead role in developing a direct funding pilot project. Its mandate as an Independent Living Resource Centre encompassed the promotion of innovative service-delivery mechanisms that enable people with disabilities to enjoy flexibility, choice and control. CILT could support ACAC by offering an administrative infrastructure, thereby strengthening the grass-roots of the disability movement.

The Consumer Coalition on Long-Term Care Reform, established in April 1992, brought together players in the disability movement to lobby for improved consumer control over disability-related services. The coalition endorsed the joint proposal developed by CAILC, ACAC and CILT for a direct funding pilot project.

The provincial government, for its part, demonstrated a willingness to work with the independent living movement. In the summer of 1992, the Minister of Health made a

commitment to test direct funding with a group of people with physical disabilities who required attendant services. The Minister agreed that Centres for Independent Living would play a key role in managing the Pilot Project. In partnership with community groups, the Ministry of Health could avoid setting up a new administrative structure to manage the Pilot Project. The partnership also enabled the Ministry of Health to impress upon the Ministry of Labour and unions that the Pilot would not take, but would rather create, jobs. As the employer, participants could discipline and, if necessary, dismiss staff who were remiss in their duties. The participants would also pay attendants according to existing wage rates and make appropriate source deductions for Employment Insurance, Worker's Compensation, Canada Pension, income tax and vacation pay.

In the spring of 1993, an amendment was passed to the *Ministry of Community and Social Services Act* that allows for direct funding (Ontario 1993). A detailed policy proposal was also developed by the partnership in 1993. Drafts were widely circulated within government and within the independent living movement. The proposal laid out the parameters for the Pilot, including eligibility criteria, service and budget parameters and selection parameters, administrative structure, and accountability mechanisms. A budget for the Pilot Project was also developed. Representatives from the partnership estimated the hourly costs and the approximate number of hours that would be required per participant.

By confining coverage to daily routines, employment-related service requirements such as note-taking were deliberately made ineligible for support. This feature was designed to ensure that employers continued to duly accommodate the disability-related needs of their employees. However, the program was designed to allow attendants to provide assistance with personal matters, such as going to the washroom, while at work or on business trips.

From the point of view of members of the independent living movement who were involved in developing the proposal, capping the number of hours at 180 per month<sup>23</sup> or its cash equivalent<sup>24</sup> was one of the key compromises made. Some people require more than 180 hours of attendant services per month. The upper limit was established in relation to the long-term care policy initiatives of the provincial government of the day.

Prohibiting participants from paying immediate family members or spouses was also a contentious issue. The Project proposal noted that an inter-ministerial working group

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<sup>23</sup> The monthly figure is based on a month of 30 days.

<sup>24</sup> Some services, such as overnight support, may be obtained by paying a flat rate rather than at an hourly rate.

intended to review the area of care-giver compensation, given that this issue crosses a number of program areas, including services to seniors, people with disabilities and children.

Another restriction placed on the Pilot concerned eligibility, which was limited to those who could and would self-manage their attendant services. That is, participants had to be both willing and able to take full responsibility for the direction and administration of their attendant services. By contrast, the initial letters submitted by CAILC, ACAC and CILT to the Ontario Minister of Community and Social Services and the Ontario Minister of Health called for a continuum of management options, ranging from self-management at one end to contracting out all management functions on the other hand (payroll, supervising staff, accounting, etc.). The Pilot proposal suggested that, pending the results of the evaluation, people who cannot demonstrate the ability to self-manage might be permitted to receive direct funding for disability-related support services under a permanent program.

In the spring of 1994, the final plank of the policy framework for the Pilot Project was put into place when regulations defining attendant services and the eligibility criteria for direct funding were passed. In June 1994, \$4.4 million were allocated to enable the Pilot Project to go forward. The announcement was made at an independent living conference convened at Woodeden Camp, near London. From all accounts, the announcement was met with great enthusiasm (Bendall 1994). Those interviewed for the study who were in attendance on that day remembered the announcement vividly, and counted it among the highlights of the Pilot Project.

The Executive Director of CILT, reflecting on the announcement, noted that the Pilot Project represents

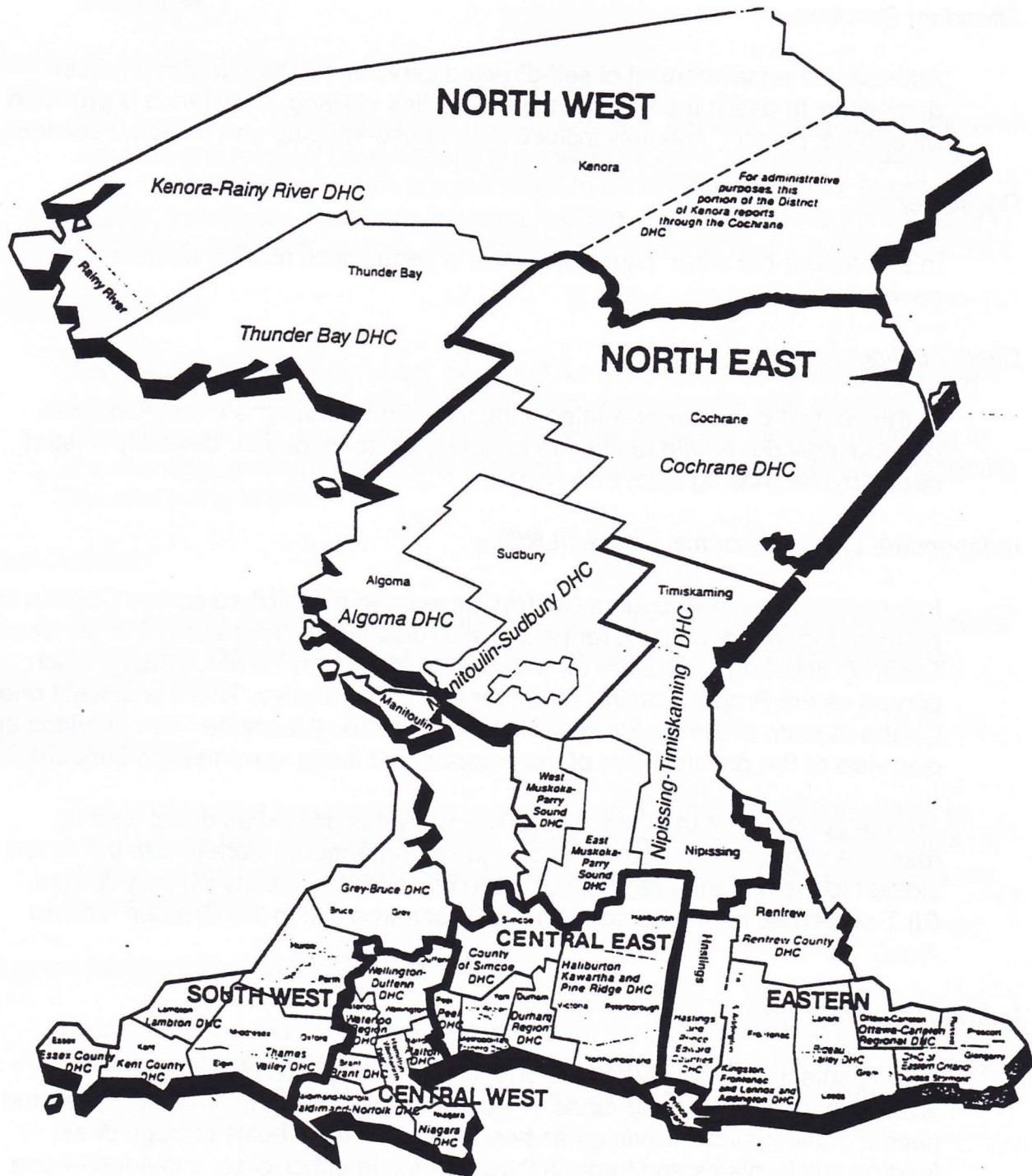
*"the culmination of years of effort using what, for most social action groups, is a different tactic — a non-victim approach. We use what's called the 'rights-bearing' approach. The IL Movement is of the mind that things such as attendant services are civil liberties issues... This approval has confirmed the veracity of that approach." (cited in Bendall 1994, p. 42)*

The importance of direct funding for enabling people with disabilities to realize their full potential was recognized by the Progressive Conservative Party of Ontario. Prior to their election in June 1995, they confirmed their commitment to continuing with the Pilot Project and indicated their desire to expand it:

*"We believe that individualized funding is the key to ensuring that people with disabilities can live full lives in their communities. The degree to which the program can be expanded must be determined within the goalposts of The Common Sense Revolution but there is a willingness to expand the program."*  
(Progressive Conservative Party of Ontario 1995, p.4)

In the spring of 1996, an additional \$750,000 was earmarked to enable another twenty-two people to begin receiving direct funding. After selection interviews were complete, it was determined that the funding was sufficient for twenty-four additional participants.

# Appendix # 4: Ontario Ministry of Health Regions



## Appendix # 5: Glossary

### *Attendant Services*

Attendant services consist of self-directed services for people with physical disabilities to assist them with routine activities of living. Assistance is provided by another person, and may include both house-keeping and personal services.

### *Consumer*

In this report, the word "consumer" means people who receive attendant services.

### *Direct funding*

In the context of disability-related supports, direct funding is a mechanism to provide individuals with funding to enable them to meet their disability-related needs by purchasing what they require.

### *Independent Living Resource Centre (ILRC)*

Independent Living Resource Centres have been established across Canada to promote independent living for people with disabilities. There are nine Centres in Ontario, including the Centre for Independent Living in Toronto (CILT), which served as the Project Administration for this Pilot initiative. There is at least one Centre in each of the six Ministry of Health regions. (Valentine 1994 provides an overview of the development of the independent living movement in Canada).

For the purposes of this Pilot, the ILRCs were designated as direct funding resource centres. The applicants and the self-managers were to use the centre closest to them in their region, but could use a different centre if they wished. CILT served as the resource centre for those who live in the Greater Toronto Area.

### *Individualized funding*

In the context of disability-related supports, individualized funding is an arrangement for allocating funds to individuals according to their disability-related needs. Individualized funding has been flowed to individuals through direct funding mechanisms and through third parties. In either case, individuals have control over how the funding is spent and what they require is determined with them.

### *Integrated Homemaker Program*

This program delivers both house-keeping and personal services to people with disabilities.

### *Outreach Attendant Services*

This program, commonly referred to as Outreach, delivers self-directed personal services and minimal house-keeping assistance, generally meal preparation only. Typically, the services are delivered in an individual's home. In order to qualify, individuals must have housing in place and demonstrate the capacity to self-direct attendant services. The maximum number of hours is 120 per month.

### *Personal Services*

For the purposes of this report, personal services include activities that people undertake in everyday living, but with which some people with physical disabilities require assistance. These activities generally include getting up in the morning, getting washed and dressed, going to the washroom, eating, going out and going to bed.

### *Self-Direction*

Self-direction, in the context of attendant services, typically refers to consumers articulating their attendant service requirements and instructing workers in meeting them.

### *Self-Management*

This Pilot Project was designed to enable people with physical disabilities to self-manage their attendant services. Self-managers are legally responsible for making all their own arrangements for attendant services. Their attendants are their employees.

### *Support Service Living Unit (SSLU)*

This program delivers self-directed attendant services to tenants renting accessible apartments in particular buildings. At least one attendant is on duty twenty-four hours per day, seven days per week. Tenants in the same building share the same attendants.

## References Cited

- Bach, M., and M. Rioux. 1996. Social policy, devolution and disability: Back to notions of the worthy poor? In *Reflections on the Canada Health and Social Transfer (CHST)*. Occasional Paper. North York, ON: The Roeher Institute.
- Badets, J. 1993. Canada's immigrants: Recent trends. *Canadian Social Trends* (Summer):8-11.
- Barnes, C. 1996. Disability and the myth of the independent researcher. *Disability & Society* 11(1):107-110.
- Bendall, L. 1994. The green light: Pilot Project will allow consumers to manage their own attendant services. *Abilities*, 41-42.
- Canada. House of Commons. 1992. *Bill C-86: An act to amend the immigration act*. 24 November. Ottawa
- Canadian Association for Community Living. 1992. *An act to amend the immigration act*. December 8. North York, ON: Brief to the Senate Committee on Social Affairs, Science and Technology.
- Centre for Independent Living in Toronto. 1994. *Evaluation plan*. 18 August. Toronto: Direct Funding Pilot Project Central Administration, Self-Managed Attendant Services in Ontario: Direct Funding Pilot Project.
- Egley, L.C. 1994a. *The cost of a national system of personal assistance services (PAS)*. Oakland: World Institute on Disability.
- Egley, L.C. 1994b. *Program models providing personal assistance services (PAS) for independent living*. 9 August. Oakland: World Institute on Disability.
- Gail V. Barrington and Associates. 1993. *Evaluation of the self managed care pilot project: Technical report*. Calgary: Alberta Health.
- Halliday, B. 1993. *Completing the circle: A report on aboriginal peoples with disabilities*. Ottawa: Standing Committee on Human Rights and Status of Disabled Persons, Queen's Printer for Canada.
- Jackson, W. 1988. *Research methods: Rules for survey design and analysis*. Scarborough: Prentice-Hall Canada.
- Kelly, K. 1995. Visible minorities: A diverse group. *Canadian Social Trends* (37):2-8.
- Kestenbaum, A. 1992. *Cash for care: The experience of Independent Living Fund clients*. Nottingham, UK: Independent Living Fund.
- Lee, R., L. Mueller, and K. Miller. 1981. age-earner status, occupational level and job satisfaction. *Journal of Vocational Behaviour* 18:362-373.
- Lord, J. 1988. *Independence and control: Today's dream, tomorrow's reality*. A review of support service needs of adults with physical disabilities in Ontario. Kitchener, ON: Centre for Research and Education in Human Services.
- Metropolitan District Health Council Working Group on Services for People with Physical Disabilities. 1996. *It's my choice: Strategic framework for services for individuals with physical disabilities in Metropolitan Toronto*. Final Report. February.

- Neysmith, S., and B. Nichols. 1994. Working conditions in Home Care: Comparing three groups of workers. *Canadian Journal on Aging* 13 (2):169-186.
- Ontario. 1991. *Bill 43: Regulated health professions act*. Toronto: Legislature Assembly, Ontario.
- Ontario. 1993. *Bill 101: An act to amend certain acts concerning long-term care*. First reading 26 November 1992, second reading 9 December 1992, third reading 3 May 1993, Royal assent 1 June 1993. Toronto: Third Session, 35th Legislature, Ontario.
- Ontario. 1994. *Ontario regulation 367/94: Grants for persons with disabilities*. Made under the Ministry of Community and Social Services Act. Made 8 June, Filed 10 June. Toronto: Legislature Assembly, Ontario.
- Ontario Advisory Council for Disabled Persons. 1988. *Independent living: The time is now*. Toronto.
- Ontario Ministry of Community and Social Services, Ministry of Health, and Ministry of Citizenship. 1991. *Redirection of long-term care and support services in Ontario*. Toronto.
- Platiel, R. 1994. Disability rate higher for natives, Statscan says. *Globe and Mail*, 26 March.
- Progressive Conservative Party of Ontario. 1995. Health and Long-Term Care Reform. *Arch-type* (May/June):2-4.
- Rioux, M. 1994. New research directions and paradigms: Disability is not measles. In *Disability Is not measles: New research paradigms in disability*, edited by M. Rioux and M. Bach. North York, ON: The Roeher Institute.
- Rioux, M., and C. Crawford. 1990. Poverty and disability: Toward a new framework for community mental health. *Canadian Journal for Community Mental Health* 9 (2):97- 109.
- Roeher Institute. 1990. *Poor places: Disability-related residential and support services*. North York, ON.
- Roeher Institute. 1991. *The power to choose: An examination of service brokerage and individualized funding as implemented by the Community Living Society*. North York, ON.
- Roeher Institute. 1993a. *Direct dollars: A study in individualized funding in Canada*. North York, ON.
- Roeher Institute. 1993b. *Nothing personal: The need for personal supports in Canada*. North York, ON.
- Roeher Institute. 1995. *Harm's way: The many faces of violence and abuse against persons with disabilities*. North York, ON.
- Statistics Canada. 1995. *National Population Health Survey overview 1994-1995*. Ottawa: Minister of Industry.
- Valentine, F. 1994. *The Canadian independent living movement: An historical overview*. June. Ottawa: Canadian Association of Independent Living Resource Centres.

Woodhill, G., V. Willi, A. Reeves, K. Chapman, A. Monette, C. Riback, H. Willis, R. McFadyen, K. Krogh, M. Sikand, and K. Yoshida. 1992. *Independent living and participation in research: A critical analysis*. Toronto: Centre for Independent Living in Toronto.



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