Self Managed Care Programs in Canada: A Report to Health Canada

June 2006

Karen Spalding, RN, PhD
Associate Professor, School of Nursing
Faculty of Community Services, Ryerson University

Jillian R. Watkins, BASc, MSc Candidate
Research Assistant

A. Paul Williams, PhD
Professor, Department of Health Policy Management and Evaluation
Faculty of Medicine, University of Toronto

This report was prepared for the Home and Continuing Care Unit of the Health Care Policy Directorate, Health Canada

ISBN: H21-294/2007E-PDF

Self Managed Care Programs in Canada

Self Managed Care Programs in Canada

1.0 Introduction

This report for Health Canada describes publicly funded, self managed home care programs at federal, provincial and territorial levels across Canada. In contrast to conventional home care programs in which care is managed and delivered by professionals or agencies on behalf of the client, in self managed programs the client takes a more active and central role both in defining needs and in determining how those needs should be met. A key characteristic of many self managed programs is that instead of funding professionals or agencies who deliver services to clients, governments directly fund clients who then purchase services from providers of their choice. A variety of clients currently use self managed home care programs including; children and families with continuing care needs, adults with physical disabilities, adults with chronic illnesses, and adults with developmental disabilities.

The major objectives of this report are to identify and describe self managed home care programs currently available across Canada through a review of Canadian literature over the past 5 years (2000-2005), a review of government websites, and a series of semi-structured telephone interviews with key informant at federal, provincial and territorial levels. The overall aims, as identified by Health Canada, are to determine:

- how eligibility for self managed care is assessed
- how self managed home care is related to consumer demand
- the likelihood of an increase in demand for self manage home care, and if so, why
- whether other issues such as program cost-containment are significant
- whether self managed care has been evaluated with respect to health status outcomes for the client, perceived client and informal caregiver satisfaction, qualify of life, effect on informal caregiver burden, effect on out-of-pocket expenses for clients and families, program liability and risks, effect on paid professional and non-professional caregivers

- what policies exist on payment to family members or other informal caregivers
- whether cost comparisons have been undertaken examining the cost differences between self managed home care and traditional home care delivery models

For the purpose of this report, self managed care programs include those programs where consumers receive funds from the government or from an agency which is government funded, to purchase home and community care services. The key difference between self managed care and traditional home care is that instead of an agency or health care professional determining when and how the individual's care will be provided, this is done by the individual themselves, or by a family or support group on their behalf. While in principle, such programs could span any range of services, in practice they tend to focus on personal activities of daily living (i.e. bathing, dressing, toileting, homemaking) that can be provided by personal care workers or health care aides as opposed to Registered Nurses (RNs).

In Section 2 we begin by providing a short background on self managed home care programs in Canada. Section 3 presents key definitions of self managed care including those used in this report and in the literature. Section 4 describes our data and methods. Findings are presented in Section 5 by jurisdiction, while Section 6 considers overall trends and issues in self managed care across jurisdictions. In Section 7 we present recommendations which highlight the need both to systematically document self managed home care programs across Canada as demand for such programs grows, and to share best practices in program design and delivery. Appendix 1 provides a description of the self managed programs in chart format and Appendix 2 lists the questions that were asked of the key informants.

2.0 Background

Traditionally home care in Canada has been provided to adults, seniors and children with acute and chronic illnesses or disabilities by health care professionals (such as doctors or nurses) or home care agencies (such as the Victorian Order of Nurses). Service users are usually assessed by a social worker or health care professional and a plan of care is developed. This model of home care fits under what has been termed a "medical model" in the sense that the patient (patiently waiting) is dependent on expert knowledge and skills both to assess needs and to deliver services For instance, in Ontario until the mid-1990s, home care services, even non-medical services like homemaking, were accessed only by referral from a physician.

In contrast, an alternate model which has slowly been growing in popularity in Canada since the 1970s, is the self managed care model (Salisbury & Collins, 1999). This model assigns the individual requiring care a more active and central role both in determining care needs and managing care. While individuals as "clients" or "consumers" may still access health care professionals including doctors, the overall care process is guided by the individual who in effect becomes the expert in their own care. The philosophy behind self managed care lies in the Independent Living Movement of the 1970's which states that people with disabilities should have the same civil rights, options, and control over choices in their lives as do people without disabilities (McDonald and Oxford, 2006). Thus, self managed care aims to give individuals the option of self-directing their care and the freedom to make their own choices (Bach, 1998).

A groundbreaking self managed care program was created in 1997 in British Columbia. A group of parents now known as the Woodland's Parents Group whose children had been institutionalised in a large facility called Woodlands School lobbied the British Columbia government for funds to support their children in the community. We note here that Woodlands School was operated by the province from 1878 to 1996; it was subsequently closed due to allegations of physical and sexual abuse. Admissions were made under the statutory authority of the Province's mental health legislation, child welfare legislation or as voluntary committals "for persons with mental disorders who required care, supervision and control for their own protection or welfare or the protection of others…" Reflecting a particular historical view of the nature and status of individuals with mental disabilities, Woodland residents were labeled "mentally retarded;" they lived in a highly structured and regimented environment away from their families (McCallum, 2001). As an alternative, the Parents Group believed that if money from the government were allocated directly to individuals, their children could live more dignified and autonomous lives in the community. In 1997 the Community Living Society was formed to assist individuals to leave Woodlands School and acquire needed supports to live within the community (Salisbury & Collins, 1999).

Such initiatives have given impetus to an apparent rise in public support for self managed care which is justified both as a step both toward empowering individuals, and gaining system-level efficiencies. For instance, in October 2002, the Report of the Community Living Transition Steering Committee to B.C.'s Minister of Children and Family Development, recommended that the government give greater emphasis to "individualised funding," a variant of self managed care, in which funds are "allocated

directly to individuals, or in the case of children, to their parents or guardians, to provide the support necessary to meet disability-related needs, and to assist individuals to become contributing citizens" (p. 25). This reflects the philosophical tenets of self-managed care: individual agency and choice. The report elaborates this philosophy by stating that individualised funding "introduces a market dynamic anchored in consumer choice that then leads to improved service quality, reduced inefficiency, lower costs and better value for money than block funded services. In addition, individuals and families who receive Individualized Funding have very high satisfaction levels because they are empowered to direct their own lives".

3.0 Definitions

Before proceeding further, it is useful to define key terms used in this report.

Consumer. The term *consumer* refers to the individual requiring care. This may include individuals with physical or developmental disabilities, chronic illness or frailty. Note that the term consumer is linked to the economic ability to purchase goods and services in health care markets. Rather than having care managed for them as "patients," and being dependent on the expertise and judgements of "expert" care providers, consumers take a more active role in determining their own needs and managing their own care, facilitated by a direct transfer of funding which allows them, or their delegates, the freedom to make choices. Consumers in effect, become the "experts." In the case of self managed care programs the consumer thus often takes on the role of direct employer of the care provider and they assume the responsibilities of an employer which may include:

- managing money, time and personnel
- applying for a business number from Revenue Canada
- making payroll deductions related to CPP, EI, Income Tax, WSIB
- keeping records for employer/employee tax purposes
- complying with provincial labour standards and human rights
- following occupational health and safety standards, and workplace safety and insurance requirements

(Centre for Independent Living Toronto (2000). *Direct Funding General Information: Self-manage your attendant services 4th Edition)*

Care Provider. The term *care provider* refers to the individual or agency providing home care services to the consumer. In the literature providers may include personal care attendants, personal support workers, non-professional care providers, and service agencies. As noted, in self managed care, the traditional hierarchical relationship between the "expert" provider, and the "non-expert" patient as receiver of care, is turned around, so that the provider works under the consumer's direction.

Self managed care. Self managed care programs provide funding for a range of personal support services to adults, seniors and children with physical and developmental disabilities, chronic illnesses, or frailty. Self managed care programs usually focus on personal activities of daily living (PADL or ADL) and instrumental activities of daily living (IADL). PADLs include eating, bathing, dressing, walking or toileting. IADLs include preparing meals, vacuuming, laundry, managing finances, using the telephone and shopping, or transportation to medical appointments. Respite services for caregivers, medical devices, or education are not generally included. The key difference between self managed care and traditional home care is that instead of an agency or health care professional determining when and how the individual's care will be provided, this is done by the individual themselves, or by a family or support group on their behalf. Rather than funding service agencies, consumers receive funds from the government or from an

agency, which is government funded to purchase services. Funds are determined based on assessed need (e.g., as determined by a case manager or health care professional such as an occupational therapist in collaboration with the consumer) or are standardised based on government regulations. Self managed care is also referred to as direct funding, individualised funding, consumer directed care, and family managed care.

Support Groups/Guardians. Support groups and/or guardians are used for the most part for individuals with developmental disabilities who do not have the capacity to manage on their own. Some programs offer the option of using a support group; other programs require one. A support group or a guardian will assist the individual in the decision making process and in the employer responsibilities if necessary.

Indirect Funding. Funds are reimbursed to the consumer or to the care provider from a government funded agency. Consumers may be reimbursed after submitting receipts, or the care providers may be paid from the agency directly. One reason for an indirect model of self managed care is to provide funds to individuals who are unable to complete the employer responsibilities of direct funding, whether due to intellectual disability, frailty or another reason (Nahmiash et al., 2000). A second reason for this model is that it enforces standardization across the board, in areas such as wages for personal care attendants, and increases accountability of public dollars (Nahmiash et al., 2000).

4.0 Methods

As noted, we employed multiple research methods including: a search of the relevant literature; a search of government websites, and semi-structured telephone interviews with key informants across Canada.

The literature search strategy, conducted by a bilingual research assistant, consisted of a systematic review of documents using Scholar's Portal, MEDLINE, Google Scholar and Google. The following terms were searched in each database: self managed care, self-managed care, self managed home care, self-managed home care, individualised funding, individualized funding, direct funding, consumer directed care, consumer directed home care, personal attendant services, personal attendant care services, personal attendant home care services, self-determination, self determination. French terms searched in these same databases include: financement individualisé, financement direct, courtage de services, services autogérés de préposés aux soins, allocation(s) directe(s), le programme d'allocations directes, allocation personnalisée.

As well, a review of the government websites for each province and territory in Canada was conducted using the same search terms as stated above; French terms were used for the government of Quebec website. Documents retained for review included those that either described or evaluated self managed care programs in Canada. Programs included in this review were ongoing within the last five years, and are publicly funded at either the federal, provincial or territorial level.

Key informant interviews were conducted with a representative from each province and territory in Canada. An attempt was made to contact a representative from every self managed care program we identified in Canada. On average, 3 – 5 phone calls

per program were attempted, for a total of approximately 67 phone calls over the course of the interview process. Representatives were individuals with detailed knowledge of the self managed care program(s) in their province. The majority of key informants were either representatives from the ministry that funds and regulates the program(s) or representatives from the agency that administers the program such as the Local Independent Living Centre (CILT) or Regional Health Authority (RHA). A series of questions (see Appendix 2) were asked of the key informants in order to clarify details of the program and seek opinions about the challenges and issues facing the program.

5.0 Findings

We identified 16 documented self managed home care programs in Canada. Programs vary significantly in terms of population served, degree of self determination, and funding mechanism. Below, we briefly describe each of these programs by jurisdiction. Appendix 1 summarizes key information about each program in chart form, also by jurisdiction.

Note, that the 16 programs we identified likely underestimates the actual number of current programs for two reasons. First, programs that did not appear on public websites and were not identified by key informants are not included.

Second, while we included programs that provide funding for personal care and daily living needs, we did not include those that provide funding solely for equipment, respite care or education. This eliminates some programs for children which have an element of self management but do not involve personal care. For example, British Columbia offers two programs for children under 18 years which provide, respectively,

educational interventions, and respite and supplies. The Autism Under Age 6 and Autism Funding Ages 6 – 18 program provides funding to families for therapeutic activities that will enable early educational intervention or supplement school based programs for their autistic children. The At Home program provides funding directly to families with children under age 18 with disabilities specifically for respite services or incontinence supplies. Likewise, Ontario's Special Services at Home (SSAH) Program provides funding of up to $3000 per year for children with a developmental or physical disability and adults with a developmental disability if they have an ongoing functional limitation and require support beyond that which is a normal family responsibility. This funding is administered through Ontario's regional Community Care Access Centres (CCACs) and may be provided for personal development and growth, which could include helping a person acquire new skills and abilities (e.g., communications skills) or family relief and support including respite, and supplies and equipment. In order to qualify consumers (individuals or parents) must provide detailed justifications how they will use the money. In December 2005, there were policy changes to allow primary caregivers to use their SSAH funding to compensate some family members for respite and/or personal development and growth.

We did not find any self managed care programs in the three Territories, or through the Department of Indian and Northern Affairs or Health Canada, First Nations and Inuit Health (personal communications).

5.1 Federal – Veterans Affairs

Veterans Independence Program (VIP). This program, offered by the federal Department of Veterans Affairs includes the option of self managed care. It is available

to Veterans who served overseas or for a period of 365 days or more, who sustained a disability during their time of service and who qualify financially. Individuals who qualify are eligible for assistance only for services related to their war time disability. Services are not available for spouses. A variety of services are available under VIP with the most common being grounds maintenance. However, personal attendant care services can also be provided as self managed care. The maximum amount of funding available under this program is $8515.77 per calendar year. The majority of consumers receive care from providers who work for an agency registered with Veterans Affairs. Consumers may choose the agency they prefer and direct their care based on the amount of funding they are eligible for. Funding can be received directly, but the majority of consumers have Veterans Affairs pay the care provider or agency, which reduces consumers' responsibilities. When consumers pay the care provider directly, they are not considered that individual's employer. Consumers must report all spending to Veterans Affairs.

5.2 British Columbia

Choices for Support in Independent Living (CSIL). This program, funded by B.C.'s Ministry of Health, provides direct funding to individuals (excluding children) with physical disabilities and individuals with both developmental and physical disabilities. The program has been in existence for the past twenty years, though it has undergone many structural changes since its inception. The program has two phases.

- Phase One is for individuals who are mentally capable of self managing their care. Consumers receive funds directly and assume full responsibility for the hiring and

training of personal attendants, and all payroll responsibilities of an employer in British Columbia.

- Phase Two is for those who are not mentally capable of managing their own care. In order to receive funding consumers must form a support group including at least five members, and they must register as a non-profit society though the British Columbia Society Act to receive funds on behalf of the individual. There are no restrictions as to who can be in the consumer support group, although family members are recommended (CSIL website).

In both Phases, a case manager determines the amount of funding an individual is eligible for and the funds are administered by the Regional Health Authority. The funding is for a care provider only and cannot be used to purchase equipment or supplies. There are currently 100 individuals in the program and there is no waiting list. The majority of consumers are between 30 and 50 years of age (personal communication).

Vela Microboard Association. Another self managed care option in British Columbia is through the Vela Microboard Association, a not for profit organisation which assists individuals with disabilities (excluding children) to access government funding for support. Under the British Columbia Society Act a group of five or more people can register as a non-profit society and gain access to funds to support one individual. Called microboards, these groups were initially started by the then Vela Housing Society in 1989; currently there are more than 350 microboards in British Columbia supporting disabled individuals. The Ministry of Social Services provides funding for the microboards. The Vela Microboard Association provides planning and support to microboard members, helping them to access community resources. The

microboards must comply with all payroll responsibilities of an employer in British Columbia (Lord et al., 2000).

5.3 Alberta

Self Managed Care Program This program is funded and regulated by Alberta's Ministry of Health and administered by the Regional Health Authorities. It is available to individuals of any age (including children) who are eligible for home care. Individuals must have a stable medical condition or care needs, requiring personal care services. Applicants are assessed by an occupational therapist who determines the number of hours of care the individual is eligible for per month. The maximum amount of funding varies across regions, from $1800/month in Red Deer to $2950/month in Calgary. The variation in funding is due to the fact that the funding levels are determined separately by each of the 9 Regional Health Authorities across the province. Non-professional service providers receive $13.35 per hour and licensed practical nurses receive $16.43 per hour. Consumers receive funds through three different streams: client managed, delegate managed and sponsor managed.

- The client managed stream is essentially direct funding. The consumer receives funds directly into their bank account, hires and trains their care provider and must assume all payroll responsibilities of an employer in Alberta.
- The delegate managed stream is for individuals who do not wish to self manage. For the most part, this stream consists of seniors who do not wish to assume employer responsibilities. In the delegate managed stream, a family member or friend can become the consumer's delegate and assume the payroll

responsibilities on their behalf, but the consumer still manages their care needs in all other regards.

- The sponsor managed stream is for consumers who are legally incapacitated. For the most part this stream is made up of individuals with developmental disabilities, seniors with dementia, and children. In the sponsor managed stream the consumer's legal guardian assumes the payroll responsibilities and assists with the direction of care (personal communication).

Individualised Funding Program. This program (established in 1989) is available through Alberta's Ministry of Seniors and Community Supports. It is administered by the Persons with Developmental Disabilities (PDD) board, a community governance structure established by legislation (Persons with Developmental Disabilities Governance Act) which consists of a provincial board and six community boards. The provincial board reports to the Ministry of Seniors and Community Supports. The majority of individuals under this program do not direct their own care although that option is available if the person is capable of taking on the responsibilities of an employer. In order to be eligible for the program, the applicant must be over 18 years of age and be assessed as having a developmental disability (defined as having significantly below average intellectual capabilities), with the onset of the disability prior to age 18. The consumer must also have at least two areas of need which require assistance. The assessment for eligibility requires some verification of their disability whether through a physician's diagnosis of the disability, or a prior educational assessment conducted in the school. There is no specific needs assessment conducted by the PDD board staff.

The majority of consumers in this program require assistance to self manage. With the aid of a family member or client service coordinator, the consumer must submit an extensive plan of care, which outlines their support and financial needs. To receive funds, the consumer must either designate a funds administrator (who can be a family member or friend), or PDD will pay the service providers directly. Under this program, the amount of funding is determined on an individual basis by a representative from PDD. If a funds administrator is needed, the consumer is eligible for up to an additional 12% of their allowance for administrative purposes (Lord et al., 2000). Currently there are 4000 individuals receiving individualised funding through PDD. The majority of these consumers receive funding from PDD and choose to enter into a contract with an agency that will provide services under contract. Only 500 consumers currently choose to hire a personal care attendant directly and take on the responsibilities of an employer (personal communication).

5.4 Saskatchewan

Individualised Funding Program. Saskatchewan's Individualised Funding Program is funded and regulated by the Ministry of Health and administered by the province's Regional Health Authorities. The program commenced in 2002 and currently serves 64 participants including children. The program is available to individuals with long term care needs who are eligible for home support services. If the consumer is mentally capable of self managing, the funds go directly to the consumer for the hiring of a care provider. If the consumer is not able to self manage, funds can be directed to a family member who manages on their behalf. The amount of funding is based on an individual assessment which is conducted by a member of the Home Care assessment

team from the Regional Health Authority. Currently there is no cap on the amount of funding available to an individual, though this may be reassessed in future. Under this program the consumer or family member must complete all payroll responsibilities of an employer in Saskatchewan (personal communication).

5.5 Manitoba

Self and Family Managed Home Care Attendant Program. This program, funded by the Ministry of Health and administered by the Regional Health Authorities (RHAs), was piloted in 1991 and became a permanent program in 1993. It provides funding for adults over the age of 16 to pay for personal attendant services. Independent Living Resource Centres provide consultation to consumers to assist them with the initial application and supportive services once the consumer is in the program (personal communication). Self and family managed programs are options for consumers who have been receiving provincial home care services for at least one year. Other eligibility criteria include being a resident of Manitoba and having a stable medical condition. Under certain circumstances individuals who do not have stable medical conditions may still be eligible, but this is assessed on a case by case basis by the RHAs. Under the self managed care option consumers receive funds directly and must act as the employer of their care provider. Under family managed care a family member or friend receives funds on behalf of the consumer and performs all the responsibilities of the employer. Consumers in the family managed care program are either not capable of self managing or choose not to undertake the responsibilities of self managing their care. Consumers are assessed by a case manager from a RHA who determines the number of hours the applicant is eligible to receive, using a standardised assessment tool. Consumers with

extremely high care needs may receive a maximum of 56 hours of care per week. Consumers receive funding at the rate of $16.01 per hour for their care provider (personal communication). Since the self managed home care program in Manitoba is run in conjunction with the regular Home Care Program, the assessment process and the amount of funding per hour is the same regardless of whether consumers receive "standard" home care or self managed home care

In the Company of Friends (ICOF). This program, funded by the Department of Family Services and administered through an agency called Living in Friendship Everyday (LIFE), serves individuals with developmental disabilities. It started as a pilot program in 1993 and has been a permanent program since 1997. It currently serves 48 consumers. Funding is allocated by a representative from the Department of Family Services. While there is no maximum amount of funding, the average for individual consumers is $6000 per year (Lord et al., 2000). LIFE staff assist applicants in developing support networks in order to help complete the application for funding, to assist with maintaining records, and managing funding and care needs. Funding is for personal attendant care services, although it can cover equipment if needed. Funding is direct to the consumer regardless of the extent of their developmental disability. With support from LIFE, consumers are responsible for all payroll responsibilities of an employer in Manitoba and must report their spending quarterly to LIFE which then reports to the Department of Family Services.

5.6 Ontario

Self Managed Attendant Service Funding Program. This program, often referred to as the Direct Funding Program, is funded by the Ontario Ministry of Health and Long

Term Care (MoHLTC). It was started as a pilot program in 1994 and became a permanent program in 1998. This program is administered primarily through the Centre for Independent Living Toronto (CILT), with CILT handling assessments and the administration of funds, and local Independent Living Centres throughout Ontario providing consultation and support services. It is available to any Ontarian over 16 years of age with a physical disability who is legally able to act as an employer in Ontario. Through the Direct Funding program consumers receive a monthly amount which must be used for the purchase of attendant care, at home or in the workplace. The maximum amount is for 6 hours of care per day. This funding can be paid through any payment arrangement desired (lump sum, hourly wage etc.). The consumer must perform all the legal requirements of an employer in Ontario and is required to report all spending to CILT. Currently there are approximately 720 people in the Direct Funding Program and approximately 310 people on the waiting list, about 40 of who have completed their initial assessment.

Brokerage Program. The Windsor-Essex Region has adopted this program for the management of supports for adults with developmental disabilities. In order to receive funding, the individual, support network, and a broker together create a person centred plan which outlines the individual's support needs (Lord et al., 2000). Brokers are provided by Windsor Essex Brokerage, a non-profit organization. Brokers do not allocate or manage funds, but rather provide assistance to individuals in applying for and receiving funds. There is no financial assessment. The consumer's budget must be approved by the Priorities Panel and by the Ministry of Community and Social Services. Funding may be used to pay for personal attendants or other supports, as needed. The

funding is provided by the area office of the Ministry of Community and Social Services. The funds are administered through a transfer payment agency of the consumer's choice, such as a community bank, which reimburses the consumer based on the expenses claimed through submission of receipts. The key informant was not able to provide details about the level of funding provided by this program.

5.7 Quebec

Direct Allocation Program. This program is funded by the provincial Department of Health and Social Services and administered by local Health and Social Services Centres, formerly called Local Community Service Centres (CLSCs). Under the program, consumers are responsible for recruiting, hiring, and supervising their care providers. Prior to 1996, consumers had the option of receiving funds directly, but this is no longer an option. Consumers receive funds through the Employment-Service Cheque Program, and are not responsible for payroll and financing responsibilities. A case manager determines the funding amount based on the consumer's needs and assigns the number of hours per week of care the consumer is eligible for. While funding levels vary by region, the maximum amount of hours (with some exceptions) is forty hours per week. Quebec is divided into 18 regions for health care planning and each local Health and Social Service Centre for the region sets the level of funding. Thus, there is variation throughout the province as to the amount of funding individuals will receive. Funding is for personal care services only since a separate program is available for the purchase of equipment. The consumer submits a Social Record form that lists the number of hours an employee worked for them, and the employee is paid by the Employment-Service-

Cheque Processing Centre. This Centre pays the employee by direct deposit, and makes the appropriate government tax deductions (Nahmiash et al. 2000).

5.8 New Brunswick

Long-term Care Program. New Brunswick offers adults over 19 years of age the option of self management of professional or non-professional services for long-term disabilities (in excess of 3 months) through this program of the Department of Family and Community Services (FCS) (NB home support). Consumers in the Long-term Care Program can opt for the self managed care option. FCS will pay a maximum of $2150 per month, and the consumer is responsible for hiring and paying their attendant care worker up to $11.25 per hour. Consumers contribute according to their ability to pay. Their contribution is determined in relation to their net family income and assets. Of the 1000 consumers using the self managed option, the majority receive indirect funding so that FCS pays the service provider directly. However, approximately 40 consumers receive their funds directly. These consumers assume all payroll responsibilities of an employer and they are responsible for any liabilities in the case of injury of to a provider (Smith, 2004).

5.9 Nova Scotia

Self Managed Attendant Care Program. From 1994 – 2005 the Halifax Independent Living Centre piloted this program with 8 individuals. On December 19, 2005 it was taken over by the Department of Health under its Continuing Care Program; the 8 individuals in the pilot program continue under its new auspices. The interview respondent was not aware whether additional consumers are now using the program. The program is for adults who are over 19 years of age who are able to self manage their own

care needs. Family members cannot receive funds on behalf of an individual nor can they be paid to provide care services. The consumer receives funding directly and must complete all payroll responsibilities of an employer in Nova Scotia. A representative from the Continuing Care Program will assess the amount of funding the consumer is eligible to receive. This amount does not correspond to the number of hours of care required. It is up to the consumer to manage their funding and determine hours and rate of pay for service providers. The consumer's personal finances are assessed and depending on income, consumers may be required to pay user fees under this program.

5.10 Prince Edward Island

Disability Supports Program. Prince Edward Island's offers the option of self management of funds under this program funded by the Ministry of Social Services and Seniors and administered by area offices. Consumers who are eligible for disability supports can choose to receive funding directly. In order to be eligible for funding, consumers must be under age 64 and reside outside of an institution. Children are eligible but our respondent did not know of any children or their parents currently using the program. The program uses a co-payment arrangement where the consumer's yearly income and the cost of their care are calculated in order to determine the amount of co-payment the consumer must contribute. A consumer with a yearly income over $170000 would not be eligible for financial assistance under the program. Before applying for the Disability Supports Program applicants must agree to pursue and access, where eligible, other publicly or privately funded assistance for disability-related supports. A case worker conducts assessments using a standardised tool which assesses the applicant's functional capabilities and determines the amount of funding the applicant is eligible to

receive. Based on the assessment, consumers are rated at one of four levels of functioning: high, moderate, low or very low. Monthly rates of assistance range from $300/month (high functioning group) to a maximum of $3000/month (very low functioning group). Consumers can receive funds directly or if they prefer they can request a third party payer. Consumers with developmental disabilities can have family members receive funds on their behalf. Consumers or family members must complete all the responsibilities of an employer in the province.

5.11 Newfoundland

Self Managed Home Support Services. In Newfoundland, this program is funded by the Department of Health and Community Services and administered through the Regional Integrated Health Authorities. Consumers who are eligible to receive provincial home supports (adults (18-64) or seniors (64+) who have a physical and/or developmental disability) can choose to have a family member receive and manage funds on their behalf. Consumers who do not have a developmental disability are eligible to receive funding directly for the hiring of a care provider Consumers are responsible for all the payroll responsibilities of an employer in Newfoundland. A case manager will assess the consumer's needs and determine the amount of funding the consumer is eligible for, to a maximum of $2707/month for an adult and $3875/month for a senior. There is no specific wait list for the self managed option but there is a wait list for the home support program.

6.0 Discussion

In the following sections we outline major issues and challenges of self managed care raised in the literature and by our respondents.

6.1 Access to Program Information.

A first major finding is that in all jurisdictions it proved difficult to access information about self managed care programs. Information is not easily found on most provincial and territorial websites and posted contact information is often incorrect or out of date. There is a significant lack of knowledge among front line workers about self managed care programs and the referrals they provided to gather details about the program were often incorrect. Interestingly, some administrators of self managed care programs are unaware of similar programs in other Canadian jurisdictions and even in their own jurisdiction. For example, staff at Choices for Supports in Independent Living in British Columbia were unaware of the Vela Microboards program in the same province, and staff at the Disability Issues Office in Manitoba were unaware of the In the Company of Friends program in Manitoba. We emphasize that this is not a criticism of our respondents; rather it emphasizes the lack of any systematic framework for gathering and communicating relevant information across Canada. In addition to making it difficult to document and assess current programs, or to share best practices, the problem of accessing relevant information is likely to pose a significant barrier for consumers, particularly those experiencing cognitive, language, or functional challenges.

6.2 Need for Program and Family Support

Program Support. While self managed care programs are seen to offer consumers potential for greater choice and autonomy, and for more efficient use of available

resources (see below), individuals with functional deficits may still require assistance to make managed care work for them and to fulfill their responsibilities as managers and employers. Some respondents questioned whether adequate program supports were available to support consumers as they purchased services on their own behalf in markets where services were often difficult to find or in short supply. For example, in Alberta, Bruce Uditzky, the Executive Director of Alberta Association for Community Living has gone on record openly criticizing the individualised funding program (Lord et al., 2000). His concerns include the lack of program supports which have been put in place to assist consumers using individualised funding. Without adequate supports consumers may be forced to give their individualised funding to agencies which in effect, manage for them, effectively eroding the principle of personal agency, and potentially, increasing costs.

Access to Family Support. Where consumers do not have full functional capacity, they may have to rely on family members to assist. However, respondents noted that family members may not always be prepared to assume responsibility for managing funding or employing caregivers. In Saskatchewan two consumer representatives mentioned that consumers with developmental disabilities have difficulties accessing the individualised funding program due to the heavy responsibilities placed on family members.

6.3 Eligibility

Eligibility criteria for the programs we reviewed vary considerably both between and within jurisdictions across Canada. Common criteria for all provincially funded programs include the requirement that the consumer must be a resident of the province in which the program is offered and be eligible for insured health care services. Eligibility

for current programs usually also depends on the age of the consumer, their ability to self manage whether due to a developmental disability or frailty, and financial status, although specifics vary widely. Moreover, programs differ substantially regarding the degree of third party involvement: while some programs explicitly require a family member, friend or support group to assist in managing care, others focus responsibilities on the consumer. Programs which cater to individuals with developmental disabilities often require a family member or support group to take on responsibility for managing care and including the responsibilities of employer.

There is also considerable variation in the process of assessing eligibility and needs. In some cases, assessment is done by a professional; in others, consumers have a more active and participatory role. In Alberta, the Self Managed Care Program requires that an occupational therapist conduct an assessment to determine hours of care per week. In Prince Edward Island workers from the Department of Social Services and Seniors use a standardised assessment tool to determine first if the individual is financially eligible and then how much funding the individual is eligible to receive. In contrast, Ontario's Self Managed Attendant Service Funding Program (for individuals with physical disabilities) uses a consumer based model where current consumers in the program sit on boards and participate in the assessment process. Applicants attend an interview with the board and the group determines together what the applicant's needs are and how much funding they will receive. In Manitoba, staff from 'In the Company of Friends', in partnership with a support network, work with consumers (individuals with developmental disabilities) to create an individual service plan.

6.4 Consumer Demand

While there was a general sense that demand for self managed care programs is growing, we found little data and no systematic population needs assessment. For example, as noted earlier, the October 2002 Report of the Community Living Transition Steering Committee to B.C.'s Minister of Children and Family Development emphasized the need to increase access to such services both as a way of increasing the autonomy and choice of individuals, and achieving cost-efficiencies in and accountability in service delivery; however, this report was more an advocacy statement than research, and as such, it provided little evidence.

Available waiting list data also suggest increasing demand, but not uniformly across jurisdictions. For example, Ontario's Direct Funding Program has an official waiting list of over 300 people, with an indeterminate number of interested individuals not formally listed. In Saskatchewan the Individualised Funding Program has seen a 28% increase in participants over the past year. In Manitoba, a representative of 'In the Company of Friends' stated that interest in and applications to their self managed care programs continue to increase. In contrast, a PEI respondent commented that there seems to be little demand for the self managed option in that province. Similarly, the Veterans Affairs representative stated that the majority of individuals choose to receive their care through a registered agency as opposed to hiring their service provider directly.

In this context, we note that consumer demand also seems to vary by needs group. In Newfoundland a key informant observed that it seems as though younger individuals with disabilities like the program more than seniors do. This observation is consistent with literature (Benjamin and Matthais, 2001) which has found that younger care

recipients compared to older recipients prefer self managed care options. Our respondents also emphasized that consumer groups for individuals with disabilities tend to be the primary advocates of self managed care programs; in Ontario 35 groups representing individuals with disabilities have formed the Individualised Funding Coalition whose aim is to advocate in favour of individualised funding programs. This pattern is associated with age and health status.

6.5 Costs

Costs constitute an important theme in discussions of self managed care. There are two key dimensions. The first has to do with the relative costs of self managed home care programs in comparison to care alternatives. While we found little publicly available comparative cost data, advocates of self managed programs contend that they have the potential to produce cost efficiencies since individuals requiring care are better qualified than third parties to understand their own needs and to find ways of meeting them within available resources. In turn, their choices as consumers will drive providers in competitive markets to be responsive and to achieve innovations in care delivery. Available evidence suggests this may be true at least in some circumstances. An evaluation of Ontario's Direct Funding Program (referred to above as *Self Managed Attendant Service Funding Program)* by the Roeher Institute (2000) concluded that the pilot program was cost effective due to a lower unit cost to provide services and a more efficient use of services. Additionally, the evaluation of the pilot program for 'In the Company of Friends' in 1996 concluded that in 12 out of the 15 cases studied, costs were 8.3% lower than other community living situations. Finally, a study conducted by Mattson-Prince, Manley and Whiteneck (1995) concluded that self managed home care

costs less than agency based home care. The 42 individuals who received funds to hire their own personal care attendants had a mean daily cost for paid care services that was 10% less than the 29 participants who used agency based care. These differences remained despite the fact that the self managed care group received on average more hours of care than the agency based care group. Mattson-Prince et al. (1995) state that the agency based care group received 10% of their care from skilled providers versus 8% in the self managed care group. This difference may explain some of the cost savings for the self managed care group as skilled providers would receive a higher wage per hour. Additionally the self managed care group received a substantially higher amount of unpaid care which could reduce the amount of paid care hours used by the self managed group.

A second dimension has to do with cost containment. Even if self managed home care programs can achieve efficiencies by driving down costs per service or per consumer, overall system costs may still increase if demand for such programs increases and if more individuals are able to gain access. This has prompted some jurisdictions to establish limits to access to existing programs. For instance, in Ontario, despite large waiting lists, access for new consumers cannot be offered unless a current consumer leaves the program or funding increases. The last funding increase occurred in 2004 when an additional 40 consumers were enrolled; however, further increases are not anticipated. In British Columbia, the Vela Microboard Association is facing wait times for the first time due to cost constraints and lack of staff. In Alberta, Persons with Developmental Disabilities has been facing budgetary constraints resulting in wait times due to lack of administrative staff.

6.6 Human Resources Shortages

Even when consumers are aware of available programs and have funding to purchase needed services, there may be few services to purchase. Limited access to suitable providers, particularly outside of urban areas, was identified as a significant problem. Representatives of self managed care programs in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Newfoundland and from Veteran's Affairs stated that consumers have difficulties finding care providers, especially in rural areas. In Quebec, a representative stated that not only do consumers have difficulties finding care providers in general, but problems with the quality of care providers arise due to lack of education and qualifications.

6.7 Outcomes for Consumers

We found evidence that self managed programs do produce desirable outcomes for consumers.

Health Status. No Canadian studies of the impact of self-managed care on health status were located. However, a 1995 study (Mattson-Prince et al., 1995) of 72 individuals with high level tetraplegia living in Colorado, USA, found that, compared to consumers who used agency based home care services, those using a self managed care model where they hired their own care providers and directed their own care, had significantly better health outcomes. This latter group reported fewer re-hospitalizations and fewer preventable complications 1 year after their injury.

Perceived Client and Informal Caregiver Satisfaction. In 2000 The Toronto-based Roeher Institute conducted an evaluation of Ontario's Individualised Quality of Life Project, which ran between 1997 and 2000. The program involved 150

individuals/families and the consumers included children aged 0-6 years, young adults (under 18) with developmental disabilities and adults with developmental disabilities living at home with parents over age 65. Under the program families received direct funding to manage the care needs of their children. The evaluation consisted of family case studies, review of files, focus groups and surveys. Almost all family participants in the evaluation indicated that their freedom and choice in daily life had been enhanced, and that opportunities to pursue personal goals had increased for both consumers and informal caregivers/family members (Roeher Institute, 2000).

Independence, Satisfaction and Quality of Life. An evaluation of microboards in British Columbia by the Women's Research Centre (1994) concluded that consumers using microboards had increased choice and opportunity. As discussed in the report by Lord et. al., (2000) the 1996 evaluation of the pilot program in Manitoba for 'In the Company of Friends' showed that consumers reported greater life satisfaction, increased self-determination, increased friendships and social interactions. As well Lord reported that a 1993 evaluation of the Alberta Health program concluded that consumers in a self managed care program had greater control over their lives, reduced stress and increased feelings of relaxation (Lord et al., 2000).

Out-of-Pocket Expenses. Self managed care programs may also benefit consumers' income in terms of the potential for gainful employment. In the 1994 evaluation of the pilot for the Ontario Direct Funding project by the Roeher Institute consumers reported that the flexibility of managing their care needs led to increased employment opportunities when using the self managed care program. While this finding

does not speak directly to out-of-pocket expenses it does address potential improvements in the financial situation of consumers.

6.8 Outcomes for Caregivers

Informal (Unpaid) Caregivers. In a study conducted by Foster, Brown, Phillips and Lepidus-Carlson (2005) researchers conducted a randomised control trial comparing consumers in self managed care programs to those in traditional home care programs. The population under study included 1433 informal caregivers of Medicaid beneficiaries in Arkansas, U.S.A who required home care services. The treatment group was provided with self managed care services while the control group used traditional agency based home care services. Telephone interviews were conducted with the informal caregivers of the Medicaid beneficiaries (the consumers) in order to assess the impact of consumer directed care on their caregiver burden. Results of the study show that self-directed care resulted in lower burdens on informal caregivers. These results were supported by the fact that informal caregivers of consumers in the self managed group were less prone to worrying about insufficient care and safety of the consumer and more likely to be satisfied with the overall care arrangement. Informal caregivers of consumers in the treatment group also reported providing slightly less care on average than caregivers of consumers in the control group, the additional free time likely contributed to lowered feelings of burden.

Formal (Paid) Caregivers. Benjamin and Matthias (2004) studied work-life differences and outcomes for 618 home care workers employed in agencies vs. those employed in self managed programs living in the state of California. The researchers concluded that for the most part there are no differences on dimensions of stress and

satisfaction between workers in agencies vs. those employed in self managed programs. Home care workers employed by agencies did however receive a higher average wage per hour (average $6.22US/hour) than workers in self managed programs (average $4.80US/hour). The evaluation of the Ontario Direct Funding model pilot (1994) found a high turnover rate amongst the self managed program employees, although high staff turnover is not uncommon across the home care sector. The evaluation also noted that employees had concerns about the lack of health benefits, fewer hours and lack of job security.

6.9 Policies on Funding and Payments to Family Members

Programs vary on the role of family members as care managers and care providers.

Funding. Programs vary on whether or not family members can receive funds on behalf of consumers. Where consumers do have the capacity to manage their own care, programs generally flow funding directly to them; where consumers don't have this capacity, funding generally flows to family members. One exception is the 'In the Company of Friends' Program in Manitoba where the family acts as a support network but all cheques are written to the consumer directly.

Payment for services. Few programs allow family members to be paid to provide care services. An exception is the microboards initiative in British Columbia where the microboard can choose a family member as care provider. The Self and Family Managed Care programs in Manitoba as well as the Self Managed Attendant Care program in Nova Scotia allow payments to family members for care services only in exceptional cases

such as where there is no other possibility of finding a care provider (e.g. in remote rural areas) or the care needs of the consumer cannot be met in any other way.

Note that prior to the mandatory implementation of the employment-cheque service in Quebec, payment of care providers "under the table" was a major issue. This practice was seen to have contributed to poor quality of service for consumers as well as low wages for attendants and even less job security.

6.10 Liability and Risks

There were no studies or evaluations which addressed program liabilities, though examination of program literature and websites indicates that in programs where the consumer must act as the employer of their care provider (which is very common throughout the programs across Canada) they are potentially liable for injuries to their care provider. A study by Matthias and Benjamin (2003) looked at abuse and neglect of consumers by their care providers in agency based services vs. self managed care models. This study found that consumers in self managed models are at no greater risk of abuse and neglect from their care providers than consumers receiving agency based care.

7.0 Recommendations

Given our findings in the sections above, we make three recommendations.

7.1 Establish a National Inventory of Self Managed Care Programs

Our first recommendation aims at establishing a national inventory of self managed care programs as a resource for policy-makers, consumers and providers. A good model for such an inventory is found in the work done by the Canadian Home Care Association (CHCA) and Health Canada which resulted in the 1998 report titled "Portraits of Canada:

An Overview of Public Home Care Programs" subsequently updated in 2003 by CHCA. This report identifies key dimensions of conventional home care programs which could be adapted to document and assess self managed programs across Canada. This would provide not only an integrated information base for the latter, but the ability to make comparisons between conventional and self managed programs and to assess possible shifts of resources and consumers between program types. Key dimensions identified in the 2003 version of "Portraits" are:

- Governance and Organization (e.g., legislation)
- Services (e.g., client eligibility, fees, service limits, guidelines, funding, program costs, service delivery models, utilization)
- Quality and Accountability (e.g., quality measures, accreditation, information systems, referrals)
- Provincial and Territorial Initiatives (e.g., emerging or planned programs)
- Challenges

7.2 Synthesize and Transfer Knowledge About Self Managed Care

Our second related recommendation emphasizes the need to gather, synthesize and transfer national and international knowledge about self-managed care programs.

Currently, it is almost impossible to answer basic questions about the costs and outcomes of self managed care programs alone, or in comparison to conventional home care programs. Because existing Canadian evidence tends to focus on novel initiatives for specific target groups using a variety of methods and approaches, it is difficult to know to what extent it can be generalized. What evidence we could find looks promising: under specific circumstances, self managed care programs may produce

favourable outcomes for individuals (e.g., independence and quality of life) and for health and social care systems (e.g., cost efficiency and cost containment). However, given the current reality of stretched budgets, growing demand, and an increasing emphasis on evidence-based decision-making, policy-makers are likely to be reluctant to support self managed home care options without a stronger evidence base.

We suggest two steps. The first is to gather and synthesize available evidence nationally and internationally. While there appear to be few relevant peer-reviewed research articles in Canada, we identified a growing "grey literature" which includes unpublished program evaluations. In addition, there appears to be a growing international literature which may provide transferable information to lead both the design and evaluation of Canadian programs.

The second step is to establish effective means for transferring relevant knowledge to the field. We note here that major national funding agencies including the Canadian Institutes of Health Research (CIHR) and the Social Sciences and Humanities Research Council of Canada (SSHRC) have recently emphasized the crucial need not only to generate new knowledge, but to transfer existing knowledge to those who can best use it. This entails not only designing user-friendly means of synthesizing and presenting research findings, but the establishment of knowledge networks involving partnerships of researchers, consumers, policy-makers and providers. Many good examples exist including the Children and Youth Home Care Network (CYHN), sponsored by SickKids Foundation, and the recently established Canadian Research Network for Care in the Community (CRNCC), based at Ryerson University and the University of Toronto, both of which aim to transfer relevant evidence and best practices

about community-based care to the broader policy community, and in the process, to stimulate support among decision-makers for investments and innovations.

7.3 Establish a Forum for Sharing "Innovations" and "Best Practices"

Our third recommendation, building on those above, emphasizes the need to transfer knowledge specifically about "innovations" and "best practices" which moves beyond identifying challenges and barriers, to formulating possible solutions. The need to develop and communicate "lessons learned" as tools for overcoming problems is now well established in many health care fields. Particularly under conditions of growing demand for costly services, but limited resources, there is seen to be a clear need to minimize costs while improving outcomes. For example, recent work on mental health and substance use disorders for Health Canada (2002) emphasizes the merit of such a constructive approach. Here, two distinctions are useful. First, while "best practices" are often defined as integrating scientific evidence or expert consensus, "innovations" may be defined more broadly to include novel approaches to care which may not yet be fully evaluated (Health Canada, 2002). In this connection, we suggest that particularly where a knowledge base is underdeveloped, as is the case in self managed home care, the documentation and dissemination of innovations can also play an important role both by identifying common or emerging problems, as well as novel (even if not fully validated) strategies or approaches for addressing them. Second, while best practices often tend to be concentrated at the clinical level (e.g. clinical practice guidelines (CPGs)), problems and gaps clearly occur at clinical, organizational, and system levels. We suggest that with respect to self managed care, systems level best practices and innovations may be

particularly important given that structures and supports need to be put in place at this level to facilitate individuals managing their own care.

Footnote. As we were finalizing this report, a study released in April, 2006, on individualized funding in Ontario, came to our attention (Lord, Kemp & Dingwall, 2006). This new study is part of an expanding "grey literature" on self managed care in the sense that it is not published per se, although it is available on a project website. We happened to find it by chance as we sought to clarify key points in our report. While this new study was not available when we did our analysis, we note here that its main conclusions are consistent with our own: individualized funding programs can produce positive outcomes including high levels of satisfaction for consumers and their families, and improved quality of life for consumers.

The fact that our key informants did not alert us to this study, and that in effect we chanced upon it, underscores the importance and relevance of our recommendations which emphasize the need to gather systematic information on self managed care, and to find innovative ways to transfer relevant and emerging knowledge to decision-makers at individual, organization, and systems levels.

8.0 References

Alberta Health and Wessness (2004). *Table D-11: Number, percentage and cost of home care clients receiving self-managed care by age group and client region (2003 boundaries).* Retrieved from: http://www.health.gov.ab.ca/regions/require/d11-02.htm

Armstrong, W. & Deber, R. (2006). *Missing pieces of the shift to home and community care: A case study of the conversion of an Alberta nursing home to a Designated Assisted Living Program*. Final Report

Bach (1998). *Securing Self-Determination: Setting the Agenda in Canada.* Retrieved from:http://members.shaw.ca/bsalisbury/Securing%20the%20Agenda%20for%20Self-Determination%20-%20Michael%20Bach.doc

Bélanger, J., Perreault, K. Bélanger, L. (1998). *L'évaluation de la phase de rodage du Chèque-Emploi-Service: le point de vue des principaux acteurs concernés.* Direction de la recherché et de l'évaluation Ministère de la Santé et des Services sociaux Gouvernement du Québec.

Benjamin, A. E. & Matthias, R. E. (2001). Age, consumer direction, and outcomes of supportive services at home. *The Gerontologist, 41(5),* 632-642.

Benjamin, A. E. & Matthias, R. E. (2004). Work life differences and outcomes for agency and consumer directed care. *The Gerontologist, 44 (4),* 479-488.

Biersdorff, K. (2002). Service funding models and individualization of services. *Rehabilitation Review, 13(3).* Retrieved from: http://www.vrri.org/rhb0302.htm

British Columbia Ministry of Health. *Home and Community Care: Choices in Supports for Independent Living.* Retrieved November 20, 2005 from:

http://www.healthservices.gov.bc.ca/hcc/csil.html

Canadian Home Care Association (2003). *Portraits of Home Care: A Picture of Progress and Innovation.* Retrieved from: http://www.cdnhomecare.on.ca/chca_admin/documents/portraits_backgrounder_nov_29_03.pdf

Centre for Independent Living Toronto. *Direct Funding.* Retrieved November 18, 2005 From: http://www.cilt.ca/funding.aspx

Centre for Independent Living Toronto (2000). *Direct Funding General Information: Self-manage your attendant services 4th Edition.* Retrieved from: http://www.cilt.ca /Documents%20of%20the%20CILT%20 Website/df_info_guide.pdf

Centre for Independent Living Toronto. *NABORS: Am I Eligible for Attendant Support?* Retrieved November 23, 2005 from: http://72.14.207.104/search?q=cache:umk2bueIlP0J:www.cilt.ca/pic/PIC%2520Directory%2520Version%25202.pdf+NABORS+cooperative+housing&hl=en

Christie, P. (2005). *Nova Scotia Budget Address: Fiscal Year 2005-2005.* Nova Scotia House of Assembly. Retrieved November 23, 2005 from: http://www.health.gov.nl.ca/health/divisions/pgmpolicy/default.htm

Community Living Transition Steering Committee (October, 2002). Final Report. *Submitted to British Columbia Ministry of Children and Family Development.* Retrieved from: http://www.cltsc.bc.ca/Final_Report.htm

Dumont-Lamasson, M., Donavan, C. & Wylie, M. (1999). *Provincial and Territorial Home Care Programs: A Synthesis for Canada.* Health Canada. Retrieved from:

http://216.239.51.104/search?q=cache:p_Hg4rbgWioJ:hc-sc.gc.ca/english/pdf/home_round/homecr-e.pdf+self-managed+home+care+attendant+program+Manitoba&hl=en#8

Foster L., Brown, R., Phillips, B. & Lepisus Carlson, B. (2005). Easing the burden of caregiving: The impact of consumer direction on primary informal caregivers in Arkansas. *The Gerontologist, 45(4),* 474-485.

Health Canada (1998) *Portraits of Home Care: An Overview of Public Home Care Programs.* Ottawa: Canada.

Health Canada (2002). *Best Practices: Concurrent Mental Health and Substance Abuse Disorders.* Minister of Public Works and Government Services Canada: Ottawa.

Lord, J., Zupko, B & Hutchinson, P. (2000). *More Choice and Control for People with Disabilities: Review of Individualized Funding and Supports.* Ontario Federation for Cerebral Palsy. Retrieved from: http://www.ofcp.on.ca/pdf/More%20Choices%20and%20 Control.pdf

Lord, J., Kemp, K. & Dingwall, C. (2006). Moving towards citizenship: A study of individualised funding in Ontario. *Submitted to the Ontario Ministry of Community and Social Services April 7, 2006.* Retrieved from: http://www.individualizedfunding.ca/MOVING%20TOWARD%20CITIZENSHIP.pdf

Matthais, R.E. and Benjamin, A.E. (2003). Abuse and neglect of clients in agency-based and consumer-directed home care. *Health and Social Work, 28(3),* 174-184.

Mattson Prince, J., Manley, M.S., Whiteneck, G.G. (1995). Self-managed versus agency-provided personal assistance care for individuals with high level

tetraplegia. *Archives of Physical Medicine and Rehabilitation, 76,* 919-23.

McCallum, D. (August, 2001) *Administrative Review of Woodlands School: The Need to Know. Submitted to B.C. Ministry of Children and Family Development.* Retrieved from: http://www.trustee.bc.ca/news_information/woodlands/Woodlands_NeedtoKnow.

McDonald, G. & Oxford, M. *History of Independent Living.* Retrieved March 28, 2006 from: http://www.acils.com/acil/ilhistory.html

Ministry of Children and Youth Services. *Special Services at Home*. Retrieved November 15, 2005 from: http://www.e-laws.gov.on.ca/DBLaws/Statutes /English/ 90m20_e.htm

Nahmiash, D., Delisle, M.A. & Carrier, J. (2000). *Best Practice Models Of Self Managed Care: Their Applications for Seniors.* Canadian Home Care Association Final Report. Retrieved from: http://www.cdnhomecare.ca/chca_admin/documents/reports__selfmanaged_care.pdf

Newfoundland Department of Health and Community Services: Programs and Policies. *Home Support Services Program.* Retrieved December 15, 2005 from: http://www.health.gov.nl.ca/health/divisions/pgmpolicy/default.htm

North Shore Disability Resource Centre (2005). *Guide to Individualised Funding.* Retrieved from: http://www.bccpd.bc.ca/i/pdf/if/GuidetoIndividualizedFunding.pdf

Nova Scotia Department of Health Continuing Care Branch (2005). *Self Managed*

Care Policy. Retrieved from: http://gov.ns.ca/health/ccs/Self_Managed_Care_Policy_Dec05.pdf

Office des personnes handicapées Québec. (1998). *Le point de vue de l'APQRIPH sur le maintien à domicile.* Magazine L'intégration.

PEI Disability Support Progam (2004). *Policy Manual.* Retrieved from: http://www.gov.pe.ca/photos/original/hss_dsp_policy.pdf

Persons with Developmental Disabilities Alberta Provincial Board (2005). *Community Inclusion Supports Framework.* Retrieved from: http://www.pdd.org/docs/prov/CISF_April_2005.pdf

Persons with Developmental Disabilities Alberta Provincial Board (2006). *Family-Managed Supports Project Report.*

Roeher Institute (2000). *Individualized Quality of Life Project: Final Evaluation Report.* Retrieved from: members.shaw.ca/bsalisbury/IQOLfinalreport.doc

Salisbury, B & Collins, D. (1999) *Is Individualised Funding About to Come Full Circle In British Columbia?* Retrieved from: http://members.shaw.ca/bsalisbury/Is%20Individualized%20Funding%20About%20to%20Come%20Full%20Circle%20in%20BC%20-%20revised.doc

Smith, E. (2004). *Home Support Services: Cost and Effect.* New Brunswick Advisory Council on the Status of Women. Retrieved November 23, 2003 from: http://www.acswcccf.nb.ca/english/documents/Final_Home_Support.pdf

Uditsky, Bruce. *The Erosion of Individualized Funding.* Retrieved from: http://members.shaw.ca/bsalisbury/The%20Erosion%20of%20Individualized%20Funding%20-%20Bruce%20Uditsky.doc

Winnipeg Independent Living Resources Centre. *Self and Family Managed Care.* Retrieved December 15, 2005 from: http://www.ilrc.mb.ca/self___family_managed_care__sf.html

Quon, A. (2005). *Disability Matters: Wishing for Self Management.* CBC News. Retrieved November 23, 2006 from: http://www.cbc.ca/news/viewpoint/vp_disabilitymatters/quon_20050218.html

9.0 Departments and/or Agencies of Key Informants

Federal: Veterans Affairs Canada

Federal: Department of Indian and Northern Affairs Adult Care Program

Federal: Health Canada, First Nations and Inuit Health

British Columbia: Ministry of Health

British Columbia: Vela Microboard Association

Alberta: Home Care

Alberta: Persons with Developmental Disabilities

Saskatchewan: Department of Health and Community Services

Manitoba: Winnipeg Independent Living Centre

Manitoba: Winnipeg Regional Health Authority

Manitoba: Living in Friendship Everyday Inc.

Manitoba: Disabilities Issues Office

Ontario: Direct Funding Program

Quebec: Ministry of Health and Social Services

Nova Scotia: Halifax Independent Living Centre

Nova Scotia: Department of Health and Continuing Supports

Prince Edward Island: Disability Supports

New Brunswick: Department of Family and Community Supports

Newfoundland: Department of Family and Community Services

Yukon: Home Care

North West Territories: Home Care

Nunavut: Home Care

Appendix 1

Chart of Self Managed Care Programs

Self Managed Care Programs in Canada

Federal Government Program

Veterans Affairs

Program Name	▪ Veterans Independence Program
Legislation	▪ Not Specified
Jurisdiction/Regulations	▪ An area counsellor assess the consumer's needs
Funding Method	▪ Consumer's have the option of billing Veteran's Affairs directly and receiving reimbursement ▪ The majority of consumer's use registered service providers and Veteran's Affairs pays the service provider directly
Funding Details	▪ Maximum amount is $8515.77 per calendar year ▪ Amount is based on health status and assessed need
Funding to Family Member	▪ A family member can be the care provider if they do not live in the same home as the consumer ▪ Program is for veterans only, spouses and family members are not eligible for benefits.
Eligibility	▪ Must have overseas service or 365 days of qualifying service ▪ Disability must be related to the wartime service ▪ Funding is only for needs related to the disability sustained while in service ▪ The program is means tested
Consumer Responsibilities	▪ Consumer is not legally considered the employer of their care provider ▪ If consumer pays the service provider directly they must keep receipts and report all spending to Veterans Affairs in order to be reimbursed
Number of Consumers	▪ Data unavailable
Waiting List/Demand	▪ No waiting list
Challenges	▪ In rural areas consumers have difficulties finding people to provide services
Evaluation	▪ None to date

Provincial Government Programs

British Columbia

Program Name	▪ Choices in Supports for Independent Living
Legislation	▪ British Columbia Society Act
Jurisdiction/Regulations	▪ Funding and regulations from the BC Ministry of Health ▪ Ministry intake unit determines eligibility ▪ Case manager determines dollar figure based on how many hours of care the client requires ▪ Support group must register under BC Society act
Funding Method	▪ Direct to client or support group ▪ Funds administered by local health authorities
Funding Details	▪ Funding for personal attendant care only ▪ Maximum of $25/hr of allowed support ▪ Support group members can be family members who do not live with client ▪ User fees required based on income level ▪ If on provincial income assistance program or GIS then user fees are waived
Funding to Family Member	▪ Yes, family members who do not live with consumer may be in the support group
Eligibility	▪ Adults (19+) with physical disabilities or with developmental disabilities combined with a physical disability ▪ Consumers with developmental disabilities must form a support group with a minimum of 5 people who will act on their behalf
Consumer Responsibilities	▪ Hiring, training personal attendants ▪ Complete all payroll responsibilities of an employer
Number of Consumers	▪ 100
Waiting List/Demand	▪ No waiting list ▪ Majority of clients are between 30 and 50 years old
Challenges	▪ Some difficulties finding personal attendants ▪ Financial funding is limited
Evaluation	▪ None to date

British Columbia

Program Name	▪ Vela Microboards
Legislation	▪ British Columbia Society Act
Jurisdiction/Regulations	▪ Funds come from Ministry of Social Services
Funding Method	▪ Funds go to the microboard, the consumer does not manage money directly,
Funding Details	▪ Funds can be used to support individual including hiring of personal supports or equipment as necessary
Funding to Family Member	▪ Yes, family members can be in microboard and service providers can also be family members if the microboard so chooses.
Eligibility	▪ Individuals who cannot self manage their care either due to a developmental disability, frailty etc.. ▪ Microboard must include at least 5 members who have a personal relationship with the client
Consumer Responsibilities	▪ Microboard must comply with gov. regulations, employment forms, bookkeeping, bank accounts, workers comp, annual general meeting ▪ Vela assists with these responsibilities
Number of Consumers	▪ 360
Waiting List/Demand	▪ Yes, there is more demand at this time then they can handle, they had 94 new microboards form in this past year
Challenges	▪ Funding ▪ Vela Microboards is having difficulty managing the demand,
Evaluation	▪ In 1994 the Women's Research Centre conducted an evaluation of Vela Microboards, key findings include: ▪ microboards provide consumers with more choice, opportunities and greater independence ▪ flexibility of funding allows for stronger connections within the community ▪ success of the microboard relies on the strength of the relationships within the microboard ▪ relationship between staff and the consumer did not demonstrate an imbalance of power

Alberta

Program Name	▪ Self Managed Care Program
Legislation	▪ Home Care Act of Alberta
Jurisdiction/Regulations	▪ Funding and regulations from the Department of Health ▪ Administered though the Health Authorities, some rules differ by region (example maximum funding amounts differ) ▪ Occupational therapist determines hours of care required
Funding Method	▪ Funds go direct to consumer's bank account or to a family member depending on stream
Funding Details	▪ Maximum amount is $2950/month, $13.35/hour pay for service provider or $16.43 licensed practical nurse ▪ Funding can be received under three different streams: client managed, delegate managed or sponsor managed depending on the consumer's ability to self manage ▪ Funding is for support services only
Funding to Family Member	▪ Yes, family member can act as a delegate or sponsor and receive funds on behalf of the consumer
Eligibility	▪ Individuals of any age with physical and sensory disabilities ▪ Must be a home care client ▪ No means testing for personal care services ▪ Must have ongoing needs throughout the day, stable medical condition or care needs, ability to manage money
Consumer Responsibilities	▪ Consumer must assume the responsibilities of an employer in Alberta, or delegate or sponsor assumes these responsibilities on the consumer's behalf
Number of Consumers	▪ 1178 as of 2003
Waiting List/Demand	▪ No waiting list ▪ Demand is not high however most popular with the young, physically disabled population
Challenges	▪ Difficulties finding service providers ▪ Difficulties with the employer responsibilities
Evaluation	▪ None to date

Alberta

Program Name	▪ Individualised Funding
Legislation	▪ Persons with Developmental Disabilities Community Governance Act
Jurisdiction/Regulations	▪ Funds and regulations come from the Ministry of Seniors and Community Supports ▪ Program is administered by Persons with Developmental Disabilities Alberta Provincial Board (PDD) ▪ PDD coordinator conducts individual assessments
Funding Method	▪ Funds go directly to the funds administrator ▪ Consumer can act as their own administrator if they are capable of self managing ▪ Consumer can appoint someone to manage funds on their behalf ▪ Funding is reimbursed after receipt of invoices or PDD can pay personal attendant directly
Funding Details	▪ No maximum amount ▪ Funds can be used in two different ways, to pay an agency of the consumer's choice to provide services, or to pay a private personal care provider ▪ Amount based on an individual service plan ▪ Family member cannot provide personal supports but can act as funds administrator
Funding to Family Member	▪ Yes, family member can act as funds administrator
Eligibility	▪ Adults (18+) with developmental disabilities ▪ Individuals must have an existing developmental disability prior to age 18 ▪ No needs testing required
Consumer Responsibilities	▪ If the consumer hires their own care provider, the funds administrator (either the consumer or a family member) must assume all the responsibilities of an employer
Number of Consumers	▪ 4000 individuals receive individual funding to contract an agency for personal supports ▪ 500 consumers hire their own care providers directly
Waiting List/Demand	▪ Interest in self managed care is growing, normally there is no waiting list however due to budgetary restrictions the assessment process is now slower
Challenges	▪ There are difficulties finding qualified people to provide services, this is across the board, not only for individualised funding
Evaluation	▪ Yes, recent evaluation completed comparing the costs of agency based provision of services and individual funding - individual funding was more cost effective

Saskatchewan

Program Name	▪ Individual Funding
Legislation	▪ Not specified
Jurisdiction/Regulations	▪ Funds and regulations come from the Ministry of Health ▪ Administration done by Regional Health Authorities under the home care program ▪ Amount of funding is determined on an individual basis through the Home Care Assessment team of the Regional Health Authority
Funding Method	▪ Funds go directly to the client or their guardian ▪ Funding is based on assessed need (by a case manager)
Funding Details	▪ Funds are for approved home supports including personal care and home management, not for professional services such as nursing ▪ No maximum amount
Funding to Family Member	▪ Yes a family member can act as a guardian
Eligibility	▪ Individual, adult or child, with long term care needs who is eligible for home support services
Consumer Responsibilities	▪ Hiring and training personal attendants ▪ All payroll responsibilities of an employer in the province ▪ Responsibilities fall on the consumer if they are able to self manage or their family member if they have a developmental disability
Number of Consumers	▪ 64
Waiting List/Demand	▪ No waiting list ▪ 28% increase in the past year
Challenges	▪ Some difficulties finding personal care attendants
Evaluation	▪ None to date

Manitoba

* Includes two programs

Program Name	▪ Self and Family Managed Home Attendant Care
Legislation	▪ Not specified
Jurisdiction/Regulations	▪ Funds and regulations come from the Ministry of Health ▪ Administration by the Regional Health Authorities ▪ Case manager from Regional Health Authority conducts assessment for eligibility with a standardised home care tool ▪ Support and consultations by the Manitoba Independent Living Centres
Funding Method	▪ Under self managed program consumers receive funding directly to their bank account ▪ Under family managed program a family member or friend receives funds on behalf of consumer
Funding Details	▪ Determined on an individual basis by a case manager from the Health Authority ▪ Max amount of funding is $16.01 per hour ▪ Max amount of hours allowed is 56
Funding to Family Member	▪ Yes, in the family managed program a family member or friend receives funds on behalf of the consumer ▪ Officially family members cannot be paid by the consumer to provide services, however in rare circumstances this rule may be waived where the person's needs cannot be met by the program
Eligibility	▪ Over the age of 16 ▪ Stable medical condition (under certain circumstances individuals without stable care needs may receive funding) ▪ Individuals in the self managed program must be capable of completing payroll responsibilities of an employer
Consumer Responsibilities	▪ Under self managed program consumer must hire, train and fire service provider ▪ Under self managed program consumer must assume the responsibilities of an employer ▪ Under family managed program a family member or friend takes on the same responsibilities as the consumer under the self managed program
Number of Consumers	▪ Data not available
Waiting List/Demand	▪ Case loads remain fairly stable
Challenges	▪ Some consumers have difficulties with initial set up of program, such as employer responsibilities
Evaluation	▪ None to date

Manitoba

Program Name	▪ In the Company of Friends (ICOF)
Legislation	▪ The Vulnerable Persons Living with a Mental Disability Act
Jurisdiction/Regulations	▪ Funded by the Department of Family Services ▪ Funding amount is determined by the Department, based on consumer's application which is supported by ICOF, ▪ Living in Friendship Everyday (LIFE) is the organisation which runs the ICOF program and provides assistance with application and ongoing support
Funding Method	▪ Direct to consumer
Funding Details	▪ Funding is for personal care attendant services or equipment as necessary ▪ Amount of funding is dependent on individual need ▪ Average amount of funding is $6000 per month ▪ No maximum amount ▪ Funding is available for 24 hour support if needed
Funding to Family Member	▪ No, family members provide supports but consumer receives cheque in their name
Eligibility	▪ Adults with developmental disabilities
Consumer Responsibilities	▪ Consumer is the employer of their personal care attendants and must abide by the responsibilities of an employer in the province ▪ Consumer must report their spending to the department quarterly ▪ Consumer is supported by ICOF in order to fulfill their payroll responsibilities, interview staff and whatever assistance they may require
Number of Consumers	▪ 48
Waiting List/Demand	▪ Recent increases in demand
Challenges	▪ Staffing is the biggest barrier, though there is a lot of flexibility and choice
Evaluation	▪ Program was evaluated in 1997 when it moved from a pilot program to a permanent program, key findings include: ▪ 14 of 15 participants reported improved quality of life ▪ 12 of 15 situations showed costs were cheaper than in traditional community living situations, on average 8.3% cheaper

Ontario

Program Name	▪ Self Managed Home Care Attendant Program
Legislation	▪ Ministry of Community and Social Services (MCSS) Act, Chapter M.20
Jurisdiction/Regulations	▪ Funding and regulations from Ministry of Health ▪ Centre for Independent Living Toronto (CILT) administers program in partnership with Independent Living Centre's (ILC's)across Ontario
Funding Method	▪ Direct to client's bank account
Funding Details	▪ Monthly amount determined individually ▪ Report spending to CILT.
Funding to Family Member	▪ No, family members cannot receive funds on behalf of the consumer not can family members be paid to provide care services
Eligibility	▪ Over age 16 ▪ Physical disability ▪ Legally able to be an employer in Ontario
Consumer Responsibilities	▪ Hire, fire, train attendants ▪ Payroll responsibilities of an employer in Ontario
Number of Consumers	▪ 725
Waiting List/Demand	▪ 40 with completed assessments, 280 applicants
Challenges	▪ Clients may need assistance finding an attendant
Evaluation	▪ In 1997 the Roeher Institute conducted an evaluation of the pilot program, key findings include: ▪ participation in the pilot enabled greater self-determination and socio-economic status for participants ▪ 89% of participants indicated they were satisfied with their participation in the pilot ▪ participants had increased opportunities in social and leisure activities outside the home ▪ the pilot was determined a cost-effective alternative to agency managed attendant service delivery for this group

Ontario

Program Name	▪ Windsor Brokerage for Personal Supports
Legislation	▪ Ministry of Community and Social Services (MCSS) Act, Chapter M.20
Jurisdiction/Regulations	▪ Funding and regulations provided by the area office of the Ministry of Community and Social Services ▪ Application first goes through a Priorities Panel and then to MCSS for allocation ▪ Brokers are provided by Windsor-Essex Brokerage brokers assist consumer to create a person centred plan which outlines their needs.
Funding Method	▪ MCSS uses a community transfer payment agency (community bank) to administer funds ▪ Consumer submits receipts to the agency and is reimbursed for approved expenses as outlined in the person centred plan.
Funding Details	▪ Funding is to hire personal care provider
Funding to Family Member	▪ Data not available
Eligibility	▪ Adults with developmental disabilities ▪ No financial means test
Consumer Responsibilities	▪ Data not available
Number of Consumers	▪ Data not available
Waiting List/Demand	▪ Data not available
Challenges	▪ Data not available
Evaluation	▪ In 1999 the Roeher Institute conducted an evaluation of the original pilot program in Windsor, key findings include: ▪ a growing sense of empowerment for families in the program ▪ the brokerage model was determined successful on a variety of features including an empowering planning process and strong partnerships

Quebec

Program Name	▪ Direct Allocation
Legislation	▪ Loi sur les services de santé et des services sociaux
Jurisdiction/Regulations	▪ Funded by the Department de Santé et Services Sociaux ▪ Administered by the Centres de Santé et Services Sociaux (CSSS) formerly the Centres Locaux de Services Communautaires (CLSC) ▪ The CSSS receives applications and determines the amount of hours of service the consumer is eligible for
Funding Method	▪ Client submits social record form and the Cheque-Emploi-Service processing centre pays personal attendant
Funding Details	▪ The maximum amount of hours per week is 40 though this may vary slightly by region ▪ Hourly wages for personal care attendants range from $7.71 - $10.25/hour it varies by region, money is for paying personal care attendants only ▪ A separate program is available for equipment
Funding to Family Member	▪ No family member cannot receive funds on behalf of consumer and family members cannot be paid to provide care services
Eligibility	▪ Adult (18+) or senior living at home with a long term disability who is capable of managing their own care needs
Consumer Responsibilities	▪ Hiring, training, scheduling of time of personal care attendant
Number of Consumers	▪ Approximately 6000 people across Quebec
Waiting List/Demand	▪ Each CSSS will have a waiting list of those waiting for their assessment to be completed ▪ No waiting list for people once their application is completed
Challenges	▪ Certain regions have difficulties finding personal care workers who are adequately trained ▪ Workers often find difficult conditions, low pay and are not interested in working as a personal care attendant
Evaluation	▪ An evaluation was completed in 1998 which examined the employment cheque service (ECS) ▪ the ECS improved the salaries of care providers and reduced under the table payments made to care providers ▪ the implementation of ECS did not affect the flexibility of the Direct Allocation program

New Brunswick

Program Name	▪ New Brunswick Home Support
Legislation	▪ Not specified
Jurisdiction/Regulations	▪ Funding and regulations come from the Department of Family and Community Services under the Long Term Care Program ▪ Consumers can choose to purchase private services as an option under the Long Term Care Program
Funding Method	▪ The majority of consumers receive funds upon invoice on a monthly basis (indirect funding), the remainder receive funds directly
Funding Details	▪ Max. $2150/month
Funding to Family Member	▪ No family members cannot receive funds on behalf of consumer and family members cannot be paid to provide care services
Eligibility	▪ Adults (19+) and seniors with significant functional limitations who qualify financially
Consumer Responsibilities	▪ Hiring personal attendant, payroll responsibilities, all liabilities in the event of injury to attendant
Number of Consumers	▪ 1000 ▪ 40 consumers receive funds directly ▪ The remainder receive funds on a monthly basis after submitting an invoice stating the amount of service that was provided
Waiting List/Demand	▪ Data not available
Challenges	▪ Data not available
Evaluation	▪ Data not available

Nova Scotia

Program Name	▪ Self Managed Attendant Care
Legislation	▪ Self-Managed Support Care Act (Bill No.179)
Jurisdiction/Regulations	▪ Formerly administered by the Halifax Independent Living Centre in a pilot program ▪ Transferred to provincial administration in December of 2005 ▪ Now funded by the Department of Health and administered by the Continuing Care Program
Funding Method	▪ Direct to client
Funding Details	▪ Funding is set at a specific amount which does not correspond to the amount of hours of care required ▪ Funds can be used to purchase equipment only if outlined in the self managed care agreement ▪ Consumers will be assessed financially and may be required to pay client fees
Funding to Family Member	▪ No, family cannot manage funds on behalf of the consumer and family members cannot be paid to provide services except in exceptional cases
Eligibility	▪ Adults (19+) who are capable of self managing their own care needs who have a long term disability existing for no less than 90 days
Consumer Responsibilities	▪ Hiring, training and firing of personal care attendants ▪ All payroll responsibilities of an employer
Number of Consumers	▪ 8 as of 2005 when administered by the Halifax Independent Living Centre, these consumers still remain in the program ▪ Data is unavailable as to how many additional consumers are now in the program.
Waiting List/Demand	▪ Date not available
Challenges	▪ Data not available
Evaluation	▪ Data not available

Prince Edward Island

Program Name	▪ Disability Support Services
Legislation	▪ Rehabilitation of Disabled Persons Act and Social Assistance Act
Jurisdiction/Regulations	▪ Funded by the Department of Social Services and Seniors (DSSS) ▪ Administered by the area offices of the DSSS ▪ Case workers conduct assessment with a screening tool
Funding Method	▪ Direct to client
Funding Details	▪ Funding is based on functional level as assessed by the screening tool ▪ Maximum amount is $3000/month ▪ Consumer receives funds directly unless they request a third party payer
Funding to Family Member	▪ Yes, consumers with developmental disability can have a family member or friend act as a trustee for funds
Eligibility	▪ Under 64 years ▪ Cannot reside in an institution ▪ Must have attempted to access all other possible resources before applying for Disability Support Services ▪ Co-payments may be required based on income
Consumer Responsibilities	▪ Consumers must keep records of their expenditures ▪ Consumer is considered the employer of their service provider and must complete all payroll responsibilities
Number of Consumers	▪ Data not available
Waiting List/Demand	▪ No waiting list, little demand
Challenges	▪ Few challenges, consumers seem to do well on the program
Evaluation	▪ None to date

Newfoundland

Program Name	▪ Self Managed Home Support Services
Legislation	▪ Not specified
Jurisdiction/Regulations	▪ Funding from the Department of Health and Community Services ▪ Funding and administrative services delivered by regional integrated health authorities ▪ Eligibility determined by a case manager or a nurse
Funding Method	▪ Option of receiving funds direct, or to sign a waiver and payment goes to either a book keeper or to the service provider
Funding Details	▪ Determined on an individual basis ▪ Max amount for a senior is $2707/month, for a person with a disability $3875/month ▪ Funds for hiring a personal care attendant, not for purchase of supplies ▪ Can include expenses related to hiring of personal care attendants such as book keeping
Funding to Family Member	▪ Yes, family member can manage funds on behalf on individual with an intellectual disability
Eligibility	▪ Adult (18-64) or senior (64+), with a physical or intellectual disability ▪ Must be able to self manage or must have a family member or close friend who can manage on their behalf
Consumer Responsibilities	▪ Direct care, take on responsibilities of an employer ▪ Must abide by all federal and provincial laws and register with Canada Revenue Agency
Number of Consumers	▪ Data not available
Waiting List/Demand	▪ Wait is for home supports, not self managed care solely ▪ Once accepted as eligible for the home support program can select the self managed option, length of wait is unknown
Challenges	▪ Consumers in rural areas have difficulties finding care providers
Evaluation	▪ None to date

Appendix 2

Questions for Key Informants

Self Managed Care in Canada: Questions for Key Informants

Respondents will be asked to confirm or provide answers to the following questions:

- What is the title of the program?

- When did it start?

- Who is eligible for self-managed care under your program?
  age, developmental or physical disability, needs test?

- Where does the funding for this program come from?
- province, ministry, intermediary, legislation, regulations?

- Is there an organisation or department responsible for administering the program?
- who are the partners?

- Who determines eligibility?
- autonomous, case manager, specific regulations, best practices?

- What is the application process?

- Is there a specific assessment tool which is used to determine the amount of care required?

- How are individuals in your program funded?
- directly, through support groups, indirectly, co-op
- details – if direct, is amount fixed, can you bank hours? If support groups, who can be in the group (family members?), if indirect, reimbursement?

- Can family members be paid to provide care services?

- What can the funding be used for?
- professional or non-professional attendant care, equipment and supplies

- What are the consumer's responsibilities?
- hiring, firing, payroll etc.

- What are the family's responsibilities?

- How many people are in the program?

- Is there a demand for your program?
- is enrolment limited, is there a waiting list?

- Is the demand for self-managed care likely to increase?

- Why do you think consumers choose the self managed program?

- What barriers are facing your program?
- cost-containment, human resources issues, logistical problems, stakeholder interests, lack of services available to rural areas, fraud?

- Has there been a formal evaluation of your program?
- results in terms of: client's health status outcomes, perceived client satisfaction, perceived caregiver satisfaction, quality of life, effect on informal caregiver burden, effect on out-of pocket expenses for client, program liability for clients, effect on paid professional caregivers, effect on paid non-professional caregivers

- Have there been any cost comparisons conducted comparing self-managed care to traditional home care delivery?

- Have there been any comparisons done on programs across provinces?