

**Home Care and Pharmaceuticals Division,  
Health Policy and Communications Branch,  
Health Canada**

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**Analysis of Interfaces Along the Continuum of Care**

**Technical Report 3:  
Adults With Physical Disabilities**

**February 2002**



**Hollander Analytical Services Ltd.**



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**Technical Report 3:  
Adults With Physical Disabilities**

**Prepared by:**

**Malcolm Anderson<sup>1</sup>  
Karen Parent<sup>1</sup>  
Marlene MacLellan<sup>2</sup>  
Janice Keefe<sup>3</sup>**

1 Department of Rehabilitation Medicine, Queen's University

2 Nova Scotia Centre on Aging, Mount Saint Vincent University

3 Department of Family Studies and Gerontology, Mount Saint Vincent University

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**Hollander Analytical Services Ltd.  
308 – 895 Fort Street  
Victoria, BC, V8W 1H7**

**Tel: (250) 384-2776  
Fax: (250) 389-0105  
info@hollanderanalytical.com**



## EXECUTIVE SUMMARY

The purpose of this report is to examine the nature and extent of integration along the continuum of care for adults with physical disabilities. The report is a synthesis of sixty telephone interviews with representatives from key stakeholder groups across the country, a focus group with consumers, and interviews with family caregivers. The focus of the interviews was a discussion of the current 'system' of care for adults with physical disabilities; what works and what does not, the barriers to developing an integrated system of care and suggestions for improving the system of care to make it more integrated.

The specific goals of this study were to identify:

- The current explicit and implicit barriers to client flow across sectors of care and to the provision of the most appropriate care in the most appropriate and cost-effective setting by the most appropriate provider;
- Whether and how funding follows services and/or individuals and if/how it flows from one sector to the other (level of fluidity between sectors);
- Inefficiencies and gaps in service availability and utilization; and,
- Ways to maximize the optimal use of available resources to achieve better client health outcomes.

An integrated delivery system is highly desirable to persons with disabilities because they often require a wide range of services and programs to address their needs. There is a growing literature emerging on integrated delivery systems. Integrated delivery, however, is only a partial description of what an 'integrated health system' implies. Along with delivery, a system of health integration is more than the coordination of care, as it embodies the authority and capacity to organize, fund and plan services for a defined, and most often, geographically-based population. That population will itself become more engaged in the maintenance of individual and community health.

In 1991 there were 4.2 million individuals in Canada who reported some form of disability (i.e., 16%) (HALS, 1991).<sup>1</sup> Of these, 2.3 million were between the ages of 15-64. Between 50% and 53% have some form of disability associated with mobility or agility, 32% have a mental disability, 25% have hearing disabilities, 9% have problems with vision and 8% have a disability associated with speech. The prevalence of disability increases with age.

It is estimated that about 33% of adults with disabilities must absorb costs related to their disability that are not recovered through any reimbursement plan (public or private), while for some persons with disabilities the costs may be substantial (Federal Task Force on Disability Issues, 1996). Sixty percent of persons with disabilities live below the poverty level (HRDC,

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<sup>1</sup> As noted in the recent document In Unison 2000, data on the nature and extent of disabilities in Canada is outdated, and heavily reliant on the Health and Activities Limitations survey of 1991 (based on 1990 data). It is anticipated that the recent funding committed to the 'Participation and Activity Limitation Survey' (PALS) for 2001 will address the data issue.

1997). Disability within the aboriginal population is almost twice the national rate (the 15-34 age group have three times the national average) (HALS, 1991).

The primary method employed in the study was a semi-structured interview with key informants in each of the provinces and territories across the country. This was enhanced by a focus group with adults with a physical disability and interviews with three family caregivers. Stakeholder groups were approached in every province and territory across the country.

Within the broad determinants of health many sectors contribute to the health and well-being of adults with physical disabilities. The findings from the study made it clear that community-based services must be developed and enhanced for adults with disabilities. An adequate income level is essential to enable the appropriate level of services to be provided while at the same time creating incentives to be more fully integrated into society without the concerns of losing income supports. The distinct lack of equipment and the removal from public funds of supplies for persons with disabilities creates a disproportionate burden on this population. There is also a huge gap in rehabilitation services – wait-lists, shortages of staff, and rural-urban inequities, that must be addressed.

Integration based on a social model of care can go a long way to addressing these issues. Integration of services is essential because of the wide array of service sectors providing care and support to those with disabilities. Independence in the community requires that community supports be integrated *around the support needs of the individual*, in which case there is considerable merit in the underlying approaches to individualized funding models whereby the client not only is at the centre of services but, where appropriate, also controls the array of services; when they are provided, for how long and by whom.

The study also emphasizes that people (family and formal caregivers) are equally important if not more so than the formal systems of care. The advocate/navigator is critical to the care of the individual. Preventive care plays a major role for individuals as do home support services and any other programs that facilitate independence. Greater levels of integration would also be enhanced by reducing the extent of variation in service availability and accessibility both within and among provinces and regions. Programs and services to facilitate independence must be developed which recognize the various strands of supports that each person with a disability must integrate into their lives on a daily basis. Governments and provider organizations need to play lead roles in concert with persons with disabilities to provide services that avoid confusion and duplication and that can be tailored to suit the often complex and varying needs of persons with disabilities.

This study has emphasized a need for further research on the issues, but at a detailed level whereby many system features for integration could be examined to fully understand what works and what does not at the micro and meso levels (i.e., client-provider interface and in regional health authorities). These considerations should embrace the knowledge that the ‘ideal system’ appears to work best at an individual level, and conceptually, ‘around’ each individual, differently depending on their unique needs. That is why self-managed care and individualized funding programs make considerable philosophical and practical sense.

## **ACKNOWLEDGEMENTS**

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## 1. INTRODUCTION

The purpose of this report<sup>2</sup> is to examine the nature and extent of integration along the continuum of care for adults with physical disabilities. The report is a synthesis of sixty telephone interviews with representatives from key stakeholder groups across the country, a focus group with consumers, and interviews with family caregivers. The focus of the interviews was a discussion of the current ‘system’ of care for adults with physical disabilities; what works and what does not, the barriers to developing an integrated system of care and suggestions for improving the system of care to make it more integrated.

The overall goals for the broader project of which this current study is a part are as follows:

1. How can we promote a continuum of integrated home and community care, with adequate links to hospitals and primary health care?
2. What supports in other sectors are essential to the success of home/community care and what are the policy options to strengthen the interface with these other sectors.

The specific goals of this study are to identify:

- The current explicit and implicit barriers to client flow across sectors of care and to the provision of the most appropriate care in the most appropriate and cost-effective setting by the most appropriate provider;
- Whether and how funding follows services and/or individuals and if/how it flows from one sector to the other (level of fluidity between sectors);
- Inefficiencies and gaps in service availability and utilization; and,
- Ways to maximize the optimal use of available resources to achieve better client health outcomes.

In the following section we outline the study methodology. This is followed by a discussion of the relevant concepts and issues surrounding services to persons with disabilities, and the extent to which models of ‘integrated delivery systems’ have incorporated service and program considerations for persons with disabilities. Following this discussion, we focus on the research findings as they relate to the existing services for this population group, and the limitations, gaps and barriers associated with ‘the system’. The interfaces of the system of care (health and other sectors) are discussed, which leads into a discussion on how key informants thought the current

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<sup>2</sup> This report is part of a larger study commissioned by the Home Care and Pharmaceuticals Division of the Health Policy and Communications Branch of Health Canada for the Federal/Provincial/Territorial Advisory Committee on Health Services (ACHS) and its Working Group on Continuing Care (WGCC). The larger study is an Analysis of Interfaces Along the Continuum of Care with specific reference to adults with physical disabilities, seniors (65 and over), persons requiring mental health services, and children with special needs. Given the wide ranging, diverse and unique needs of persons with disabilities and the myriad of services and programs that are provided, we have focused the study on adults with physical disabilities. Many of the findings, however, are salient to the broader disability community.

system of care for adults with physical disabilities could be improved. We then present data from the consumer focus group and the interviews with individual family caregivers. The paper concludes with a synthesis of the findings and considerations for future development of a system of care for adults with physical disabilities.

## **2. METHODOLOGY**

The primary method employed in the study was a semi-structured interview with key informants in each of the provinces and territories across the country. This was enhanced by a focus group with adults with a physical disability and interviews with three family caregivers. Stakeholder groups were approached in every province and territory across the country. On average, about five to six interviews were conducted in each province and territory, for a combined total of sixty interviews. Key informants came from various parts of government, organizations responsible for the coordination and/or the delivery of care (e.g., regional health authorities, CLSCs, Health Districts), provider agencies, long-term care facilities, illness/disease associations, consumer associations and advocacy groups (a list of these is provided in Appendix 1).

Given that the sample size for interviews was very small, the researchers sought to obtain as wide a cross section of responses as possible. The final list of interviewees for the study was based primarily on the contacts that the researchers already had with stakeholders in the various jurisdictions, and a snowballing sampling strategy whereby key informants identified other individuals that would provide valuable insight to the subject matter.

The key informant was contacted and asked if they would be willing to participate in the study. The research team provided a one-page project summary, a list of services that adults with physical disabilities would typically receive, and a list of questions that would provide the basis for the interviews. Additional written material was sometimes sent to the researcher following the interview (see Appendices 2-4 for the material used by the research team and study participants). The four researchers each took responsibility for conducting interviews in different parts of the country.

A focus group was conducted with adults with physical disabilities in Kingston, Ontario. A range of issues were discussed and centered on the system of care for individuals and how to improve the provision of services and programs. Interviews were also conducted with three family caregivers regarding the issues they face when dealing with the system of care for adults with physical disabilities. Questions used in these focus groups are presented in Appendix 5.

### 3. THE COMPLEXITY OF DISABILITY

In 1991 there were 4.2 million individuals in Canada who reported some form of disability (i.e., 16%) (HALS, 1991).<sup>3</sup> Of these, 2.3 million were between the ages of 15-64. Between 50% and 53% have some form of disability associated with mobility or agility, 32% have a mental disability, 25% have hearing disabilities, 9% have problems with vision and 8% have a disability associated with speech. The prevalence of disability increases with age.

It is estimated that about 33% of adults with disabilities must absorb costs related to their disability that are not recovered through any reimbursement plan (public or private), while for some persons with disabilities the costs may be substantial (Federal Task Force on Disability Issues, 1996). Sixty percent of persons with disabilities live below the poverty level (HRDC, 1997). Disability within the aboriginal population is almost twice the national rate (the 15-34 age group have three times the national average) (HALS, 1991).

There is complexity and diversity in the disability population. First, it is as diverse as the general population (e.g., age, gender, living arrangements, location, attitudes, ethnic background and so on). Second, there are many types of disabilities, severity varies from one person to another and may also fluctuate for individuals over the course of their lives. Third, some individuals may have a disability from birth while others may acquire a disability at some point in their lives. Fourth, some diseases may be progressive with the disability becoming more severe over time while others remain constant. Fifth, some individuals may also have other illnesses that affect their physical, emotional, mental and spiritual health.

When each person's economic context and capacity for various employment opportunities are incorporated it is obvious that any discussion of persons with disabilities must either be very detailed and specific, or at a level which speaks of general themes and issues that are applicable across what is an extremely heterogeneous population. Similarly, the array of services and programs to address the unique and generic needs of persons with disabilities is extensive and requires the engagement of many different sectors and parts of government. These can yet again be stratified according to jurisdictional level (federal, provincial, regional, municipal), and the various conditions that persons with disabilities may have. And while specific services may be required, persons with disabilities also use the 'regular' programs and services used by the general population. There is also definitional ambiguity regarding the term 'disability'.

Given this context, the study, mainly because of its breadth, explores the issues surrounding the coordination and integration of services and programs for a system of care for adults with physical disabilities. Similarly, given the context, the short time-frame for the study (6 months), and the sample size for the interviews, we have used a broad level of analysis.

There are a number of definitions of 'disability'. Some definitions can be inclusive while others restrictive, and can thus be used in different ways (e.g., for broad discussions, or for restricting

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<sup>3</sup> As noted in the recent document *In Unison 2000*, data on the nature and extent of disabilities in Canada is outdated, and heavily reliant on the Health and Activities Limitations survey of 1991 (based on 1990 data). It is anticipated that the recent funding committed to the 'Participation and Activity Limitation Survey' (PALS) for 2001 will address the data issue.

access or rationing programs and services). Traditional medical approaches refer to disability in terms of treatment or illness, while the now more commonly accepted socio-political approach is to move from notions of incapacity to capacity of persons with a disability and the capacity of the social and political environment to support and enhance life according to the needs of those individuals. As recognized by the World Health Organization, disability involves an interaction between the individual and the environment. There has been a fundamental shift in philosophy, from one of paternalism to one that focuses on independence and responsibility.

A number of reports have been produced since the 1980s to further the understanding of disability issues and to improve services and programs (e.g., Obstacles Report (1981), A Consensus for Action (1990), Mainstream Review (1993), Completing the Circle (1993), The Grand Design (1995), and Equal Citizenship for Canadians with Disabilities: The Will to Act (1996)). The recent report, *In Unison* (FPT, 1998), provides a vision for a Canadian approach to disability issues that builds upon the concept of full citizenship for persons with disabilities (this has been expanded upon in *In Unison 2000* (FPT, 2000)). As the 1998 document notes, “*The full participation of persons with disabilities requires the commitment of all segments of society*”. *The realization of the vision will allow persons with disabilities to maximize their independence and enhance their well-being through access to required supports and the elimination of barriers that prevent their full participation*” (p8).

Three building blocks are identified by the 1998 *In Unison* report: Disability supports, Employment and Income. The document observes that initial efforts by governments should address issues of *efficiency and effectiveness of programs and the coordination between programs* (italics added). The disability supports include a range of goods, services and supports tailored to the individual requirements for daily living. These include technical aids and devices, special equipment, home support services (e.g., attendant care, homemaking), physiotherapy, occupational therapy and life skills. There should be a flexible and responsive delivery of these supports, as well as enhanced access and portability to ensure that personal and economic independence is maximized. Beatty et al (1998) note that consumer-directed personal assistance services are associated with high levels of satisfaction relative to personal assistance services that are not consumer-directed. These points are directly relevant to the current paper.

There has been a positive impact from the development of independent living resource centers (ILRCs) on individuals and communities (Hutchison et al, 1996). Hutchison and others emphasize the importance of the community in enhancing the level of independence for persons with disabilities. Another increasingly popular form of support is an individualized funding model in which care is publicly funded but directed by the individual with a disability. This model has several variants but essentially provides control and flexibility for individuals, as well as enhancing independence and being cost effective.

The *In Unison* document is consistent with the philosophical shift towards independence in that it emphasizes full citizenship with a movement away from government responsibility to shared responsibility, a shift from program-centred approaches to person-centred approaches, and from multiple access requirements to integrated access requirements. In short, there is recognition of the need to be more responsive to the wide and variable range of needs of persons with disabilities and to provide programs and services that are flexible and can enhance independence

and full participation in the community. A social model of care is responsive to the needs of persons with disabilities because of the mostly chronic nature of the disabilities and the fact that the community setting is the basis of everyday life.

Given this context, this paper reports on the extent to which a 'system of support' exists for persons with disabilities across the country, the degree to which integration is occurring and areas that need to be developed. The academic literature on integration and services for persons with disabilities is very limited in this regard. Although the literature on health integration suggests that an organized delivery system is characterized by elements such as focusing on community health needs, matching services with these needs, and coordination and integration of care across the continuum (Leatt et al, 2000; Shortell, 1996), there is very little in the way of explanation as to how these can best be operationalized, and no examination as to how integrated delivery models could work in a social model of care for persons with disabilities.

#### 4. INTEGRATED SERVICES

An integrated delivery system is highly desirable to persons with disabilities because they often require a wide range of services and programs to address their needs. There is a growing literature emerging on integrated delivery systems. Integrated delivery, however, is only a partial description of what an 'integrated health system' implies. Along with delivery, a system of health integration is more than the coordination of care, as it embodies the authority and capacity to organize, fund and plan services for a defined, and most often, geographically-based population. That population will itself become more engaged in the maintenance of individual and community health.

'Health Integration' combines health care's component parts in order to achieve a unified system designed to maintain and enhance the health of all individuals within the system. Most discussions of an integrated health system (e.g., Closson et al,1996; Leatt et al;1996, 2000; Leggat and Leatt, 1997) use Shortell's definition of organized delivery systems, which he defines as a network of organizations that provides or arranges to provide a coordinated continuum of services to a defined community and is held clinically and fiscally accountable for the outcomes and health status of those served (Conrad and Shortell, 1996; Shortell et al, 1993; Shortell et al, 1995; Shortell et al, 1996).

Health integration systems attempt to place increased emphasis on public health, illness prevention, disease management, health education and health promotion, and to meet the needs of the population they serve. In keeping with the trend from institutional care to community-based care, an integrated delivery system would provide a full range of care (acute and chronic institutional and ambulatory care, rehabilitation and home care services) (Anderson and Brazil, 1995; Closson et al, 1996; Leatt et al, 2000; Marriott and Mable,1996; 2000; Meeks, 1993; Ontario Nurses Association, 1996). The language of integration is sometimes confusing and full of jargon. In many cases, although 'the patient/client' or the broader 'public' is implicit in many discussions of health integration, their importance and centrality is often understated.

In the context of persons with disabilities the literature on health system integration has several shortcomings. First, the 'system of care' requires a much broader conceptualization of 'health' that includes well-being and quality of life constructs and the social model of care. Second, there needs to be greater recognition of the necessary engagement of many different services and programs, typically offered by a range of government departments. In this regard the issues center on the effective coordination of service moreso than issues surrounding integration. Third, the literature and model development of integrated delivery assumes conventional service provision that presently does not accommodate individualized funding arrangements for persons with disabilities. These are successful initiatives that provide flexibility and choice for persons with disabilities but are noticeably absent in discussions surrounding integrated delivery. Fourth, the literature on integration does not fully acknowledge the significant role that community-based agencies and volunteers play in supporting the needs of persons with disabilities. Fifth, there is still an emphasis on the medical model of care in the literature on integration, which as noted earlier, is in contrast to the prevailing socio-political approach which embraces the social model of support that better reflects the lives and needs of persons with disabilities.

One of the key elements, and indeed, rationales for greater levels of coordination and integration is improved, timely access to services and programs. This can be enhanced considerably through a single point of access into programs and services, and the effective coordination of services through a care coordinator (often also referred to as a case manager). Integrated or not, an effective 'system of care' for each individual with a disability is reflected in minimal assessments, timely flow of information, full awareness of services and programs by both the individual and the myriad of providers, and the avoidance of duplication.

A 'system of support' for persons with disabilities encompasses a wide range of health and social services that are funded and /or delivered by the provincial and territorial governments. These include health, community and social services, income support, housing, transportation, employment and education. An individual will use each sector in different ways depending on their specific needs. Ideally, there is a mosaic of services that are effectively coordinated and integrated with one another, reflecting unique 'systems of support' for each individual. The reality, however, as the remainder of the report will show, is that there is still much work to be done for this to be fully realized.

## 5. EXISTING SYSTEMS OF SUPPORT

### 5.1 Overview

*“The system is set up to wear you down”*

*“Dealing with my illness is easier than dealing with the system”*

The definition of who was included in the “*physically disabled net*” was a reoccurring theme in some interviews. While some respondents used a strict definition, other respondents feared they were too broad to make sure no one fell through the cracks. This definitional ambiguity is consistent with the literature and numerous reports by governments in Canada and internationally.

The existing systems of care are diverse and complex, with a wide range of services and programs provided in some form to persons with disabilities. There is a range of access and a mix of predominantly public and some private provision both within and among provinces and territories, which makes a comprehensive profile of services offered extremely problematic.

Inadequate availability of services in one sector can mean that people often are inappropriately placed in another, the most common example for adults with physical disabilities being the lack of affordable, accessible and well-designed housing. This sometimes means that people must live in long term care facilities.

Most services in the list of services (Appendix 3) of the interview protocol (Appendix 4) were publicly available to varying degrees in at least some areas of all the jurisdictions. Eligibility for services, however, was variable across the country and within jurisdictions, which in itself is a major issue for persons with disabilities. With the exception of acute care, services are offered by both the public and private sectors. Not-for-profit agencies play a major role in the system, ranging from advocacy to being major providers of equipment for clients.

People with disabilities were ‘hit hard’ by the economic downturn in the mid-1990s and the recovery that occurred was slower for people with disabilities than others. Over the past decade there has been a reorganization and reshuffling of responsibilities associated with the containment of costs in health care in the provinces and territories. For some jurisdictions this has meant the creation of new ministries/departments by combining existing ones, or it has meant regionalization. All provinces and territories have been challenged in various ways to continue to meet a high demand for services within a context that includes physician shortages, work interruptions, public sector discontent, shortages of qualified professionals (particularly rehabilitation specialists), shortages of para-professionals such as homemakers (partly due to low wages and poor working conditions), regional disparities and inequities in services between rural and urban areas.

Entry to a system of care for adults with physical disabilities was similar across the country. The most common routes were self-referral, through the acute care system as a result of an accident or sudden health issue, or the movement from youth programs to adult programs. Family physicians, community services, home care, adult protection, and discharge planners were also

identified as entry points into the system. While individuals can and do move between types and locations of services, “*navigation*” or “*way-finding*” is not easy since the onus rests mainly on the client or their family caregiver or advocate to determine options.

The ‘one-way valve’ that occurs as acute care settings look to shift more care out of the hospitals into the community is considered an issue by stakeholders. There is very little the community can do, however, because of the power differential with hospitals, so although the acute care hospital may make ‘savings’ with more care shifted to the community, the community must absorb the additional costs of new clients in the system.

Another significant issue is the role of physicians, especially neurologists, who may provide care for individuals with muscular dystrophy, spinal cord injuries, acquired brain injury and so on. Their availability has a significant bearing on the rest of the health system. One respondent gave the example of a neurologist moving to the United States. The ‘system’ was immediately compromised as the two other neurologists must pick up the load, which results in even longer waiting lists. In the meantime, individuals requiring the specialist care have little option but to access the system through the emergency department. There is clearly a strong interrelationship amongst various parts of the system.

There are a number of organizations across the country that work to improve the systems of care for adults with physical disabilities by providing services, advocating for individuals and lobbying government for more and better coordination of services (e.g., there is the Alberta Disabilities Forum – an alliance of over 1,000 disability organizations in the province).

## **5.2 Self-Managed Care and Individualized Funding Models**

There is a strong desire and commitment by those with physical disabilities to live independently in the community to the greatest extent possible. Facility-based care is seen as a last resort when supports cannot be provided in the community setting. “*They are warehousing people while they wait to die*”. Facilities are often perceived as not having sufficient consumer focus and not providing adults with physical disabilities dignity and choice, which is consistent with the dominant theme that persons with disabilities should live as independently as possible.

Self-managed attendant services were considered to be “*the most important of all the services*”. The availability of self-managed care, however, is only on a limited basis across the country. Self-managed care not only places an individual at the center (the client-centered approach), it gives the individual ‘control’. This is an important distinction in the disabilities community as this ‘client-driven’ approach places the individual as an active participant in their own ‘system of support’ rather than a passive recipient of care in a broader array of services within various programs.

The Direct Funding Program in Ontario is one example of a self managed care model that gives an adult with a physical disability the opportunity to manage a budget, hire and supervise their own care attendants. Funds are provided by the Ontario Ministry of Health, administered by the Center for Independent Living in Toronto (CILT), and provided monthly to individuals who can

schedule their care needs according to what best suits their life. These can be provided at any site the individual requires the service (e.g., home, work, community).

A self-managed care model is also used to varying degrees in the CLSCs in Quebec. The *allocations directe* is based on a CLSC assessing clients on their care needs and the appropriateness of the managed model for the client. The client will hire the attendant care worker and manage the care provided while the funding for the worker is provided by the CLSC. The model works well for certain individuals, and is regarded as very cost-effective. In British Columbia meanwhile, a new cooperative model of self-managed care is being piloted based on 6-8 clients (all with disabilities) and 4-5 workers, all of whom know the care needs of the clients they serve.

Substantial concern was expressed across the country that the social side of support – home support services in particular – are being cut and access to these services is becoming more restrictive through changing eligibility criteria.<sup>4</sup> Meal programs were cited as being critical to the ability for adults with physical disabilities to live independently. Adult day support programs were also considered important.

Most stakeholders observed that the social model of support “*makes more sense*” than the medical model for adults with physical disabilities because of the emphasis on ongoing support to enable independence in the community. Respondents observed that the medical model places too much emphasis on physical health and not enough emphasis on psycho-social health. As one Albertan stakeholder commented, “*many issues of disability are not health-related, they’re community support issues*”.

The key to improved services for adults with physical disabilities was the concept that positive change should be based on a client-centered approach, whereby the money follows the client and transcends administrative barriers. Positive directions were noted in many provinces, including the development of single entry points, the development of inter-ministerial committees within provinces and an increased openness for all sectors to work together.

### **5.3 Income and Employment**

The health care system, observed respondents, does not incorporate in its policy and planning what is going on in the employment ‘system’. “*We’re constantly facing a barrage of cutbacks in services – why do we bother to work?*”

Income levels are considered inadequate for adults with physical disabilities, given all their unique needs (e.g., for transportation, housing supports, equipment and so on). Employment programs were seen as important, but often there is insufficient funding allocated to these programs. In addition, the income restrictions for accessing income supports from the

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<sup>4</sup> In British Columbia there is an organization – the Home Support Action Group – whose specific focus is the need to maintain and enhance the role that home support services play and to prevent the ongoing erosion of these publicly funded services.

government work as disincentives for people to develop or work through employment outreach programs.

When compared to other population groups such as seniors, the policies for accessing the system have even more restrictive means tests (i.e., through income support programs). Essentially any income that an individual earns is expected to be applied against the cost of care. Attendant services, transportation, technical aids and prescriptions were generally available to individuals although in many cases the extent of this availability was a function of the income level of the individual; it is more likely that those on social assistance do not have to pay for services.

Vocational services were available for clients that have '*realistic*' potential of deriving benefit from them; this was believed to be a core service, although lacking in availability. An issue identified by one respondent was the lack of services for the disability population following the age of retirement. In one province workshops and vocational training can be used by individuals for up to 20 years; new entrants to the system were not able to find spaces because they were occupied by older clients. Employment programs were also available, but these services were not part of the continuing care system.

Respondents were very realistic about the services that should be considered as core services in a fully integrated system; few espoused public funding for everything. There is a need to improve eligibility levels for income support so that more people in lower income brackets would be eligible for publicly funded programs and services. Infrastructure funding for volunteer organizations is essential as they have increasingly assumed (or been assigned) important roles in the community care system. Support for volunteer groups was generally couched with a caveat that volunteers are a way for communities to "*give back*" and are, in fact, "*avenues for healthy communities*".

## **6. LIMITS, GAPS AND BARRIERS TO INTEGRATION**

### **6.1 Limitations**

#### **6.1.1 Overview**

There was general consensus amongst stakeholders that services are not being offered as effectively as they could be. There were many reasons cited regarding the ineffectiveness of services across the country. These included:

- lack of consumer involvement in planning for services;
- lack of effective communication among providers;
- lack of recognition of the needs of adults with physical disabilities;
- inappropriate placement because of lack of options;
- regionalization (one respondent referred to regionalization as downloading care decisions to an un-elected level from an elected provincial level, thus transferring blame for problems);
- regional disparities within provinces;
- ineffective single entry programs;
- bureaucracy (including departmentalization and turf wars); and
- limited resources.

#### **6.1.2 Priorities and Unmet Needs**

To many consumer groups, the priorities established by decision-makers in government and regional health authorities make it clear that adults with physical disabilities are given low priority when compared to many other competing budgets (e.g., hospitals, physicians, drugs, etc.). Services not provided through the public system are accessed privately, but adults with physical disabilities often do not have the financial means to obtain the required services.<sup>5</sup>

One major outcome of ineffective service provision is that unmet needs may escalate to a higher level. Despite the expressed need for more funding, respondents in some provinces felt that the money that was available was being put to good use. Others, however, felt that there was still too much emphasis on the medical model of care and insufficient attention given to the social model of support in the community. “Cost-effectiveness” it was stated, is only one dimension of evaluating care, and it is not necessarily associated with “quality”. Not-for-Profit organizations in the community were cited as examples of lean, effective operations.

Decisions must be made as to how much the public system pays, and for what. The implications are that if the system does not pay then the individual will have to either absorb the costs or simply do without the service, equipment, supplies, etc. In some cases this may lead to decisions on whether to move into a long term care facility or not. When the public system does not pay

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<sup>5</sup> When a standard wheelchair may cost around \$4,000 it is easy to understand the concerns of consumers that the cost of such equipment hopefully will rest with the public system. Equipment may also be outdated through the publicly funded programs.

for services then typically there are gaps in provision because the population does not have the means to pay for services privately.

Difficulties can arise because a client is sometimes not the purchaser of services but rather the recipient of a program. For example, the government may pay a per diem if the client is in a facility, but no support is available in other settings, thus effectively removing ‘choice’ for some clients. There was little awareness of funding incentives among the community-based respondents.

### 6.1.3 Transition from Youth to Adult

The transition from youth to adult supports is a major issue in many provinces. Programs for youth are generally much better than the adult programs. The transition is very disruptive and often results in a decline in the level of support that can be provided. In one province, for example, there are problems with financial supports when a child turns 18 years of age. Once 18, the criteria for acceptance in the support program is to have a disability that is “*severe and long term*”. In most cases, individuals are refused the first time they apply because of the very loose criteria that are applied. What is more the issue, however, is that individuals cannot apply *until* they turn 18. So this, coupled with typically not being successful on the first application, means that many people must wait a year before receiving the new adult income support. The government has put an asset testing limitation on the program, which effectively means that the applicant must virtually be “*broke*” to access the program. A key problem here, as one stakeholder commented, is that the disability program is seen as a welfare program, when in actual fact it should be considered as an entitlement.

### 6.1.4 Individual Incomes

*Income is essential – “it is the basic thing – a basic determinant of health”*

*“Income is at the root of where it all begins ...as it does  
have a certain amount of impact on health”.*

Central to any system of care, integrated or otherwise, is the ability for individuals to have sufficient income to maintain a quality of life that is not compromised by their disability. Given the unique needs of adults with physical disabilities, income support is widely regarded as inadequate. This places the individual in a mode of dependency on the state to provide the required services and programs, and increases the reliance on support from family, friends and volunteer organizations. This ‘informal’ component of the support structure is facing growing pressure as the responsibility for support is being shifted from the public sectors.

Income support is ‘*extremely modest*’ across the country. If family members or spouses were not able to assist or supplement an individual with the disability then the person may in fact be unable to “survive”.

*“As soon as you start making money the government “claws back”. You can make up to \$175.00, then after that you are deducted \$1 for every \$1 you make. You soon hit the ‘welfare wall’. It’s a major disincentive to work”.*

*“The financial system is very discriminating, 30% of your income needs to go to accommodating the disability. There are hidden costs such as clothing, attendant care, equipment, supplies etc.”*

*“The insurance industry is also a problem for people with disabilities. Pro-rated at \$300.00/ month to access basic blue cross. Drugs aren’t covered - unless you have \$1 coming in you lose drug benefits. It can come down to medication versus food”.*

There is limited opportunity to move monies across the publicly funded sectors. In one regionalized system, for example, there is a new initiative to integrate the home support program to provide services to the over *and* under 65 groups (historically they have been separate but increasingly provinces are including persons with disabilities in their programs). While achieving integration at one level, at another level it also has the potential to reduce flexibility. For example a stakeholder in one province spoke about the loss of flexibility in the provision of services when the home life support program moved from Community Services to Health and stopped accepting new clients. Although related to mental health needs, the following quote is equally indicative of the situation for adults with disabilities: *“This program enabled many younger mental disabled to stay at home – we no longer have the capacity, nor this safety net, and if home care can’t respond in a timely fashion these people may end up in a facility”.*

## **6.2 Gaps**

### **6.2.1 Overview**

*“If we didn’t have transportation we would be stuck at home. And if we didn’t have home supports, we would be stuck in bed. How does that make me a citizen?”*

Gaps in health and social services exist across the country. These gaps are not discrete but are interlinked in complex ways with varying effects on clients. Gaps were identified in transportation, housing, home support services, meal programs, vocational training, equipment and aids, medication programs, follow-up after discharge, and case management. Ironically, these are the very services that support and maintain people in community settings. Inadequate or incomplete education for both the formal and informal sectors broadened these gaps, as did communication problems between sectors, multiple assessments, the different priorities of each sector and defensiveness between departments. The end result extended beyond the significant lack of support and services to individuals, to affect the system in its entirety.

Lack of services in one area altered the demand for services in another. Efforts to maximize effectiveness in delivery are hindered because the demand agenda is set by factors other than the level of client need. Difficulties experienced by people are often the result of “system factors” rather than disabilities. Most often, clients are pushed into higher levels of care, and get stuck

there, because the lower end services are simply not available. For integration to be truly effective, it must be tailored to the needs of the individual.

Even when services existed, the capacity to address client needs is often very limited, and there are restrictive eligibility criteria and long waiting lists. Inadequate services are creating a culture of unnecessary reliance and dependence – for example, inadequate vocational training and limited access to equipment or transportation curtailing work opportunities, leave little options but for individuals to access disability income/social assistance. Speech language and occupational therapy were also identified as gaps in services. Occupational therapy, in particular, was mentioned repeatedly by stakeholders across the country as a major gap in the system.

### 6.2.2 Transportation

Having access to transportation is essential to adults with physical disabilities. If individual transportation is not available or beyond the financial means of most people, then there is a heavy dependency on effective publicly funded transportation services. The mention of the adequacy of transportation (and equipment), however, generally elicited laughter from respondents in the community sector; publicly funded transportation for persons with disabilities is limited.

There are similar transportation issues across the country. There are several access issues. Although there can be parallel transportation services available when compared to the regular transit system for the public, there are fewer hours of service operation, price differentials, waiting lists for service and a number of issues to resolve regarding priority-setting for use of the system (e.g., someone using it for work purposes versus someone with medical appointments?).

Access to transportation is another issue associated with regionalization. In one province, for example, the provincial transport agency has now made buses more accessible but the regions all have to agree to this. As a result, consumer groups have had to lobby every region, which should not be necessary, and is also very time consuming. This is indicative of the rest of the country.

### 6.2.3 Housing

Many respondents referred to inadequacies in the accessibility, affordability and availability of housing units for adults with physical disability. Even when there were some units available, they were seldom designed for families, and the location could be problematic given the lack of transportation. In some regions of the country, there was little in the way of co-op or not-for-profit housing alternatives as well as limited subsidies. Long waiting lists further frustrated clients. For those persons with their own homes, if they need to make a capital investment so their home is accessible they will typically have to absorb the majority of the cost. Only a small amount is rebated back through taxes.

*“The housing supports available are generally for seniors and not for adults with disabilities which is extremely problematic. If you try to help people with disabilities*

*through only the tax system you are going to miss many who do not have an income and who survive on an GAI (Guaranteed Annual Income).”*

One individual commented that group homes were being used more frequently to save money, but in fact it served to ghettoize people with disabilities. In many regions of the country, group homes primarily housed those with an intellectual disability.

#### 6.2.4 Home Support Services

A major issue for the disability community is the loss and lack of emphasis on home support services (prevention and maintenance functions) as more acute, medically-oriented care places a budgetary squeeze on the services that address the needs of the chronically ill. This is observed for home support services right through to the commitment to funding for prevention of lung disease. Although acute care services are necessary, it was clear that respondents felt the needs of the chronically ill are not being adequately addressed.

Another important point raised is that even though ‘gaps’ in service may not exist per se, there has been an erosion of services that has compromised the independence and health of persons with disabilities. Again, the examples cited refer to the reductions in home support services in various parts of the country. In other words, services may be available but the hours of service may be quite limited when compared to 5-10 years ago.

#### 6.2.5 Equipment

Many respondents commented on the lack of access to equipment and supplies. Accessibility in terms of location was also cited as an issue – provincial programs such as SAIL (Saskatchewan Aids to Independent Living), for example, are not conveniently located for many people living in rural communities. One piece of equipment, for example, was available through the publicly funded system in a province but was considered to be outdated. The same piece of equipment meanwhile, was not available through the publicly funded system of another province, but a Consumer Association was able to subsidize its purchase for some individuals. There were concerns voiced by respondents in one province meanwhile, that adult day programs are available to people with developmental delays, but not for people with acquired brain injury.

#### 6.2.6 Rural-Urban Differences

The amount of the service gaps ranged significantly depending on the location in the province. All respondents referred to inequities in accessibility of services throughout their province. Geography was a significant issue, one that also has various levels of intensity. For example, the distance, time and expense of having to travel to St. John’s, Newfoundland from a remote area in Labrador to access assessment and treatment facilities is different from traveling from many other regions within the Atlantic provinces.

There are frequent inappropriate placements of individuals in higher levels of care because of the lack of community supports in the more rural and remote areas, particularly in the areas of housing options and equipment. People seeking respite have extremely narrow placement

options. Adults with a physical disability may be placed in a nursing home with older people, which is inappropriate.

### 6.2.7 Attitude Gap

Finally, another gap identified was the ‘*Attitude Gap*’. There needs to be a shift in thinking away from viewing people with disabilities as ‘sick’, and therefore needing services, to thinking of them through a citizenry approach as outlined in the *In Unison* document. That is, people with disabilities “*Are who they are*” but in order to participate more fully, society needs to be more accessible and society must itself, improve its attitudes towards persons with disabilities. A change in thinking is occurring but it needs to be sustained and expanded as part of the shift towards a more integrated socially-based system of care.

## 6.3 **Barriers To Integration**

### 6.3.1 Overview

In general, systemic barriers such as the organization of administrative entities, departmental competition and budget allocations make it very difficult to have funds follow the client, both within the set of services targeted to those with physical disabilities and among the broader health and social service sectors. While respondents conceded that it could happen and one respondent indicated that it happened in the shift from institutional to community based care, the majority indicated that seldom did the funds follow the client, and that it occurred on an informal basis because of an individual intervention.<sup>6</sup>

*“We’ve built parallel systems for adults with disabilities”*

### 6.3.2 The Need for a System ‘Vision’

Integration calls for a vision of a “system of care” that transcends the constructed barriers of organizational and functional design. Respondents in the study observed that there is not necessarily a system of care, although system elements are evident. Lack of political will and the supply/demand dynamic directed by both professionals and public policies were cited as factors that segment the wide range of services and prevent them from being an integrated cohesive system.

Many government departments are involved in providing a system of care for adults with physical disabilities. Services and programs based in separate departments may have policies that are in conflict with one another. The problem exists if, as one respondent put it, “*the client doesn’t have anyone to walk him or her through the system – to connect the dots – there is a problem. The result is that the person goes without a needed service and eventually ends up in a far more difficult situation requiring even greater resources.*”

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<sup>6</sup> In one case there was an effort to secure extra funding to enable a ventilator dependent person to move from acute care to long term care.

There are services that case managers would like to access but are unable to because they are not directly part of the long-term care system. This means a client must apply for assistance from such areas as subsidized housing, income assistance, vocational assistance and employment support. In such situations, the key factors that hinder integration include the:

- lack of clarity among various agencies and organizations about each other's role and responsibilities; and,
- protection of 'turf' (budget, resources etc.) – the concern about losing power and resources rather than thinking of the issues to address from the client's perspective.

There is little discretion available at the "front-line" for workers to allocate resources more appropriately to meet the needs of clients. Case managers are often in internal conflict as they have to balance cost containment with client advocacy.

### 6.3.3 Underlying Philosophies

Underlying philosophies are formidable barriers (e.g., one province's focus on "care" rather than on "independence"). Philosophical differences also exist between departments from which the clients access services. Some departments are mandated to help the client achieve the optimal level of service and to advocate when appropriate while others, particularly the income support programs, are seen as fiscally-driven; the client must fight for any concession that is allocated to them. Delays occur in the delivery of services as the processing of assessments and claims can occur over timelines that are not congruent between government departments. This alludes to the close interrelationship between integration and the timeliness of service; integration will not be truly effective if it does not lead to reduced time to process the various service options for an individual with a disability.

### 6.3.4 Funding

Lack of funding has been a barrier to integration in that it has translated into cuts in programs or very limited capacity in most components of the system. This means that individuals may not be accessing the most effective programs or services relative to their needs, needs that could be addressed more effectively if the system was integrated 'around the client'.

The vision and funding commitment must reassert the significant need for integration, especially in situations where the lack of service in one sector affects other sectors. For example, if regulations in home care mean that an individual can only be provided three hours of nursing care per day, s/he may not be able to return to the community and must remain in an acute care bed (or Long Term Care bed), thus "blocking" the ability or capacity of that service to respond to someone whose needs may better match the service. The health professional, through assessment and their decision-making role, holds the balance of power in deciding where and when the person can move through the continuum.

Funding alone, however, is not a panacea. As many respondents pointed out, change also requires new models of partnership, responsibility and delivery. All respondents noted major

gaps in the “transference” pieces – the interfaces – between the acute and community sectors, which is heightened by regional disparities and rural/urban issues.

### 6.3.5 Health System Design

Lack of alternatives drives the inappropriate placement of clients. One interesting barrier identified related to general health care (the type of care that is available to, and promoted for, all members of a community), such as prostate and gynecological exams. Often appropriate equipment was not available in health offices to facilitate this routine care; persons with disabilities often are not receiving basic preventive services, which in turn affects their health outcomes. Indeed, a caution was raised that family doctors have to treat more than “*the physical disability in routine check-ups*”.

The current reductions to home support services across the country was considered as simply “*wrong*” by many respondents as it reflects the prevailing medical model approach to disability and not the social model of ‘*living assistance support*’ and independence.<sup>7</sup>

### 6.3.6 Regionalization

A major barrier to integration has been regionalization. In the western provinces the regional health authorities are considered to have caused a number of problems and gaps in services to emerge. As one BC stakeholder commented “*it is one of the worst things that’s happened to adults with disabilities ... people find it a formidable task to move across the street*”. In many programs funding does not follow the individual. If someone moves from one region to another adjacent region, often they will have to be reassessed by the new region, thus contributing to overall inefficiencies in the provincial ‘system’ of care. The same range of services may not be available, and/or the individuals may not be eligible for some of the services in other regions within a province.

In one instance, an individual with a brain injury faced significant delays with assessment. When able to be discharged, the hospital planned to discharge the individual into a rehabilitation setting, but three hours away from their family’s place in another region. Only following the family’s perseverance did they achieve a satisfactory resolution of the matter for the individual and the family. The case reflects very poor communication and coordination amongst the three regions that were involved. In another instance, a person with a disability was offered a new job in a different region to the one in which they lived. But they risked losing services if they moved, “*there was no guarantee of getting them in [new region], and [person] may have lost the ground [they] gained in [current region] ... these are fellow citizens in Canada*”.

The situation is compounded when considering unique housing needs, as this has a major bearing on the mobility of adults with physical disabilities. If there is not sufficient housing to address

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<sup>7</sup> In British Columbia there is growing emphasis on meals on wheels to replace meal preparation. But meals on wheels may be difficult for people as it requires bending over and heating the meal. If individuals have to pay for these meals themselves, this can lead to fewer meals being eaten (because of low incomes), and preferences being made by consumers as to how to spend their limited income.

the needs of adults with physical disabilities then they may not be able to take on new employment in another region, even before issues surrounding services availability and eligibility are considered.<sup>8</sup>

*“we’re deconstructing systems that were set up years ago when we were trying to make all inclusive societies”.*

Finally, in one province equity in service access became particularly evident when a regionalized system was put in place. Services in one part of a province were integrated into the long-term care system but were left outside such a system in another area because of lack of resources and insufficient population size to warrant the services.

### 6.3.7 Lack of Case Management

Coordination is the lynchpin for integration, achieved through effective case management. There is a lack of case management for people when they return to the community, resulting in many unmet needs. This is further exacerbated by the general lack of knowledge of how to access services, what is available and what is most suited to circumstances. Sometimes, it was noted, users of services are reluctant to share information about an excellent service they receive for fear that increased demand will result in service cutbacks.

Even when case managers are available on a limited capacity as a ‘system navigator’, high caseloads act as a hindrance to integration. Time pressures also affect the ability to come up with creative solutions to improving integration. As one respondent suggested *“There is not a lot of time to think of how to make it better”.*

Families are the main source of support for individuals in the community but they receive little assistance in this role. Many expectations have been put on families and the reality is that there is sometimes no family available, or they are not able to take on this major role for a variety of reasons, or do not themselves, have the capacity to navigate what is considered to be a complex array of services and bureaucracy.

Having a “client advocate” – that is, a strong family member advocating for everything – is seen as essential, otherwise the services an individual may receive may be fairly limited, advocates *“are absolutely invaluable.”* Families, however, are not always knowledgeable on how best to navigate ‘the system’, which is one of the areas in which volunteer groups have also become invaluable. As one government official commented *“I don’t know where we’d be without the volunteer sector.”* The families of adults with physical disabilities, however, typically receive very little support from government.

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<sup>8</sup> One stakeholder, in fact, suggested that the lack of portability even within jurisdictions could even be a Charter of Rights issue.

### 6.3.8 Eligibility Assessment and Criteria

*“The way you are assessed often determines the services you will receive, so it is important to be able to have standardized assessment tools to ensure equity and fairness.”*

*“Eligibility criteria [are] a real maze—they’re all so different.”*

Both clients and service providers are affected by the barriers to integration created by the complexity of multiple assessments, differing eligibility criteria, the limited sharing of information, and varying resources. There are different rules for eligibility criteria depending on the type of service that is provided. For example, in one province, financial assessment in long-term care excludes RRSP income but includes these dollars in home support. Within home support the maximum dollars allocated for services varies by whether it is the over 65 population or the under 65 population.

### 6.3.9 Lack of Communication

The concept of integration assumes a web of interactions and communications between and among a large number of stakeholders. Respondents pointed to the gaps in communication that foster isolation rather than integration. Communication is ineffective between the system and clients, between public and private sectors, and within the entire system. Community-based organizations and agencies believe that there is limited knowledge and recognition, by the government departments, of their strengths and capacities. They want to participate at the policy level and feel they have much to contribute. There was acknowledgement, however, of several initiatives across the country that are designed to improve the channels of communication. Respondents desire more opportunities for different sectors to come together for discussion, planning and design.

### 6.3.10 The Uniqueness of Northern Canada

*“Our population has all the needs of southern centers but the numbers aren’t there”*

The limitations, gaps, and barriers that exist in the north are just like southern Canada only that the remoteness makes the problems even more difficult. Persons with disabilities are disadvantaged in the North because economies of scale do not exist to provide the services that are much more readily available in the southern parts of Canada. Programs and services that may be available (e.g., day programming) may be directed more to the geriatric population and thus may not be appropriate to meet the different needs of the disability population. Equipment meanwhile, is limited and may take a long time in being sent to the northern communities.

As with southern Canada there is no one program that addresses services for people with disabilities.<sup>9</sup> The nature and extent of service delivery is significantly different between the major centers (e.g., Whitehorse and Yellowknife) and the small remote communities scattered over the territories.

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<sup>9</sup> In the Yukon every program area has its own intake/assessment tool and criteria for applying. There is no accurate determination of the number of adults with disabilities in the Yukon.

In the smaller northern communities it typically takes a crisis to occur before changes in services are made for a person with disabilities. Respite care is a “*huge unmet need*”. Occasionally it is provided, but only in crisis situations, even though respite care is recognized as playing an instrumental role in preventing these crises occurring in the first place.

The provision of technical aids, equipment and supplies is often highly variable in the northern territories. As in some areas of southern Canada, the cost for these is being shifted to the consumer, away from the publicly funded system. Further, in the territories there is often a long waiting period for equipment and supplies to arrive once they have been ordered – “*it’s basically who you know, where you are and how good your advocate is*” that will determine the extent of these supports that an individual will receive.

Program mandates do not necessarily flow in to one another, and “*service delivery is not as flexible as it should be*”. More day programs and self-managed attendant services are required: “*attendant services are not well managed in Yukon, no-one seems to have the mandate to do that*”.

Wheelchair accessible transportation linkages are very limited in the Northwest Territories (NWT). There is no public transportation for adults with physical disabilities except for the small community of Holman on Victoria Island. Apart from Holman there is no Handi-bus for persons with disabilities, even in Yellowknife (There is a Handi-van for Seniors, but that is heavily booked with the seniors community).<sup>10</sup>

In the NWT there is no self-managed care and a lack of adult day support: “*There is not enough meaningful activities available for anyone with any disability*”. The main concern is the lack of social support in the community, including a lack of adult day support. As a result, providers see adults with physical disabilities present more with crisis situations than anything else.

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<sup>10</sup> There is only one taxi in Yellowknife that can take a wheelchair, which costs an extra \$6 booking and a \$6 fare.

## 7. INTERFACES WITHIN AND BETWEEN CARE SYSTEMS

A number of strengths with the interfaces between systems were cited by respondents, many of which offer considerable potential to be developed to further enhance the interfaces of care and support. The amalgamation of facility sites in one province and the integration of primary and tertiary care, for example, were viewed as positive for clients in easing their movement from one service to another. Other strengths noted in various parts of the country included:

- Emerging and evident will of providers and government to improve the interfaces through working together;
- Reorganization of government departments;
- Liaison role (nurse) in an extramural program effectively links facilities and communities;
- Regulations such as those affecting interpretation, public accessibility, employment issues (“100 rule: employers with more than 100 employees must have a certain percentage of employees who have disabilities), and human rights legislation;
- Shared knowledge generated by those who have been through the system;
- There are people working in the system who really care; and
- Access to rehabilitation services and effective, integrated plans of care.

In some Atlantic areas the regional health boards were considered as the key to linkages between systems. Community Health Centres were identified as ways in which health programs could be linked together. The provinces were focusing on having their senior management personnel meet with various sectors on inter-departmental committees to discuss gaps and conflicts within existing policies, and strategies to overcome these gaps. The interfaces between community services, housing and health were common at these discussions. Part of the difficulty in the system is the lack of awareness of the different stakeholder policies and the implications for the clients. While these collaborative efforts were generally praised by the government officials, the coming together was not without its challenges. As one respondent explained, *“sorting out conflicting policies has the potential to make things work for the client however achieving consensus on what to do isn’t easy”*.

Several examples were provided that show a commitment to furthering the integration of services. These initiatives had the common theme of cross-sectoral partnerships focused on client needs. One Not-for-Profit agency, for example, initiated a gathering of rehabilitation professionals from twelve different groups to discuss a vision of an integrated system.

Another initiative is a recent program whose goal is to separate services to persons with disability from income support. This program will enable adults with a physical disability to earn income and still qualify for services by using a co-payment scale to access services. The basis of the new program is a person-centered care management approach in which all groups (departmental representatives) that are involved in supporting the person with disabilities, as well as the person and his/her advocate, will meet to insure an integrated approach to the delivery of services. This further exemplifies the notion of a system of support around an individual as opposed to a system of support at a broader level in which individuals must ‘fit’.

A recent initiative involving a Rehabilitative Services Plan was successful in some regions where the leadership saw the need for integration as a priority. This resulted in the formation of committees of various stakeholders (e.g., Nursing homes, public health, education, family and community services and Extra Mural Program) to focus on clients at the center and identifying the service goals and current gaps and/or duplication of services.

At the micro-level, respondents observed that it is the people in the health care system, rather than any particular systemic element, that are important facilitators of integration. Those in the field, be it primary, acute, home care or long term care, were said to have “*compassion*”.

Case management, particularly as part of a single entry system, was considered to be essential to the effective integration of services. While some respondents disliked the phrase ‘case management’ because of not wishing to be referred to as a ‘case’ and objected to the notion of ‘management’, others noted that it is the case manager who knows the system and the community, and in addition to assessment, can cross-cut sectoral barriers to seek the supports that the individual requires.

At the meso and macro-levels, the necessary factors for supporting integrated services were as follows:

- enabling and appropriate policies;
- appropriate eligibility criteria;
- appropriate levels of funding;
- adequate availability of services; and
- increased consumer awareness to foster an informed public.

Despite the strengths, however, the interfaces between programs and services within the health system and between these and other related sectors are not well developed. Respondents recognized that efforts are being made by government to address this through inter-ministerial committees, partnerships, inter-sectoral collaboration, and formalized agency collaboration through community-based ‘accords’. This is a very positive shift as it places the client more at the center of his or her support system.

At the individual level, the lack of a comprehensive and integrated care plan affects one’s ability to access a range of services. In some cases one may not even know what other service options exist. Several respondents commented on turf wars at the agency level as agencies ‘compete’ for clients to ensure their funding levels are not reduced (as they are provided funding on a per capita basis). For the individual, lack of integration can mean that “*people don’t seem to have anyone to help them through the system*”. It was felt that the interface between the acute and community sector was very limited when a client moves from a rehabilitation hospital in the city to their home in a rural area. There was little follow-up.

A number of other factors are problematic for the development of systems of care for adults with disabilities. These include:

- In the current environment of limited resources, it is tough to be creative to develop further integration without it being formalized by the system – *“people who are stressed are not creative.”*;
- There is a human resource shortage; competition is evident between employers, and this may limit the extent of informal integration;
- Money is spent ineffectively (e.g., using ambulances to transport disabled people in rural areas where there are no appropriate transportation services);
- Extra costs are being incurred by people who wish to remain at home;
- General inadequacy in training across all groups of employees and all sectors; and
- Lack of understanding about various service and program capabilities.

There are promising signs that there is more commitment to developing systems of care tailored to client need rather than existing administrative or bureaucratic structures. To consumer organizations, however, the wheels of change are moving slowly even though the problems have been identified for a number of years. It is at the interfaces of various sectors, systems, and programs, and between the range of providers and funders, that change is most required for adults with disabilities. Perhaps even moreso for this population than any other given their complex, diverse and changing care and support needs.

## 8. HOW TO IMPROVE INTEGRATION

Creative and innovative options were suggested by respondents as avenues to improving integration. These options were directed either at the system level or the community level and incorporated a commitment to enhanced understanding.

### 8.1 System Level

**Develop enabling frameworks:** Policies are enabling frameworks, reflecting values and priorities. As guidelines, policies must support independent living for persons with disabilities by ensuring that options are available and adequate, and by ensuring that appropriate services are offered to support the person rather than to accommodate existing systems. The *In Unison* document was cited as an effective policy foundation for persons with disabilities. One approach to promote inter-sectoral collaboration was to ensure that all departments within a defined community share the same geographical boundaries for regions/districts (currently, departments often define regions/districts differently). Accreditation was recognized as promoting integration as it encourages facilities to examine services.

**Review all policies through a Disability Inclusion Lens.** There are several initiatives in provinces that are developing the means to review policies from the perspective of the individual with a disability.

**Develop a more centralized model:** One respondent suggested that eliminating the regional structure, returning to a centralized delivery model, and thus restoring political responsibility to the province, would be effective. Some respondents indicated that changes in the system need to include a move away from a system that fosters dependency because of limited options, to one that empowers people with choices.

Many respondents alluded to changes in attitudes as necessary prerequisites, such as seeing institutions as a community resource rather than places to be avoided. In addition, keeping focused on the broader picture and working together may encourage better understanding of each other's strengths and the capacity to respond to client's needs. An emphasis on a "social model" of care is necessary for a continuum that encompasses broad health and social sectors.

**Link services to outcomes:** A better understanding of outcomes, supported by evidence, and how the provision of services is linked to these outcomes would help further an understanding of what are essentially the broad determinants of health – a concept that these community-based agencies embrace in their everyday actions. The health care system, to be effective, must not exist in isolation, nor can it operate effectively without including all sectors, including the private sector.

**A role for the federal government:** Two respondents felt that the federal government should take a leadership role in coordinating disability services, with secure funding dedicated through the provinces. This was based on a concern that the provinces simply were not doing enough for persons with disabilities and that if the federal government was looking for a role to play in health care, integrating and sustaining care delivery systems for person with disabilities would be

a valuable contribution. Indeed, given the wide variation in access to services and supports both within and between provinces, the federal government could play a central role in improving the consistency of services and supports to ensure equal access regardless of location for individuals with a disability.

**Improved integration amongst government departments:** There needs to be greater integration amongst the various government departments that are responsible for providing services to adults with disabilities. These include departments on housing, transportation, health, social services, employment and income. This segmentation is at the crux of the issue for adults with disabilities as it is difficult to have a unifying client-centered approach when so many different departments are involved, with different requirements, different assessments and different focal points of someone's life. Such an integrated government model should also involve representation from senior bureaucrats in each department who are familiar with the array of services and policy changes underway in their respective departments, plus representation from people with disabilities themselves – especially those individuals who have strong links with the grass-roots disabilities community.

**More targeted funding:** There needs to be more targeted funding directed, and expanded, into home support services, *“If they can do it for doctors they can certainly do it for us, but they don't”*. Through greater use of home support services there would be considerable benefits to consumers and the system in a number of ways. For example, more people would be employed, and more would be healthier: *“The government needs to help people to live instead of just existing – we'll all be much healthier, which would put less pressure on the medical model”*.

**Individualized funding and self-managed care:** There was also a call for more individualized funding and a stronger emphasis on a client-centered approach whereby the funding was for the individual and was not flowed through a number of different government departments and programs. Self-managed care was considered an important option that should be available so long as the person with the disability has the capacity to deal with the administrative aspects. There should be training or support for this, as is the case in some programs. Small organizations are being set-up in Alberta, for example, to run the business side of self-managed care for people with disabilities.

## 8.2 Community Level

**Draw on current community expertise:** A common theme was that there must be recognition of the strengths and existing expertise in the community. A mandate to improve integration was not only the purvey of government, but required a willingness to expand boundaries to include community agencies and consumers, as expressed in the phrase *“need to really listen”*.

**Develop an enhanced community supports model:** An enhanced community supports model with a single point of entry was strongly recommended to foster integration. If there are not sufficient community supports in place then catastrophic events may occur and individuals may involuntarily have to be institutionalized.

**Increase role of Peer support:** Greater emphasis should be placed on peer-support to improve the system, which would also involve much more of the social model of care and a blend of the informal and formal supports of care. In fact, to some stakeholders, it is felt that adults with physical disabilities enter the formal system of care initially through the medical model through contact with professionals. This is hard to break away from and a dependency on professional supports develops.

**Expand the volunteer sector:** The role of the volunteer-sector could be expanded so that volunteers could assist persons with disabilities to be integrated into the community while maintaining as much independence as possible.

**Consumers should have a greater role in developing a new integrated system:** Adults with physical disabilities want to have a say in the policies, programs and services that directly affect them. Their expertise adds a new dimension to integration. Meaningful opportunities for consumers to participate need to be fostered in an integrated system.

### 8.3 Awareness

**Improved capacity for empowerment:** The capacity of adults with disabilities to be better engaged in the process of care for themselves needs to be improved. This involves a range of factors, including the development of effective decision-making skills, strong advocacy skills (*“everyone has a self-advocacy role”*), the ability to communicate effectively (with the system), and the ability to educate various service system providers about the care needs of people with disabilities.

**Improve communication:** Effective communication is critical within and among sectors and about services. There is a desire to emphasize client-centered support rather than system-centered, with ongoing case management and effective single entry access. Overcoming barriers among sectors and departments requires a *“leap of faith”*, a commitment to fostering (and sometimes generating) trust between sectors to overcome fear that support for another service might mean a reduction in funding to your own service. Governments can play a leadership role in creating a profile of each respective player’s mandate, funding and operations (or resource capacity).

**Educate the public about role of prevention:** There is a need to educate the public on preventive health care, to support the environment (in their own home/community) and to encourage networking at the community level. There is a tendency to put money on the acute care services that often can create dependency. Recent initiatives proposed in the review of community services in Nova Scotia with the ‘Kendrick Report’ argued strongly for more community based options and for consumer directed care. This client-centered model was mentioned several times in the Atlantic provinces as a way to integrate the system.

Respondents in provinces that were not yet in a regionalized system believed that regionalization was the way to improve the system for persons with disabilities. By moving the ownership and management of the system to the community level/regional level these groups can develop a service system to better meet the needs of their community. In contrast, however, many

respondents in the western provinces were highly critical of regionalization because it meant that service access, portability and availability were highly variable amongst the regions.

Improvement in the extent of integration could be achieved by having a policy filter so that any changes in policy would be discussed and measured in terms of their proposed impact on other systems (In Nova Scotia, some of this horizontal policy planning is being undertaken by the Policy Advisory Council).

## **9. CONSUMER PERSPECTIVES: ADULTS WITH PHYSICAL DISABILITIES AND FAMILY CAREGIVERS**

### **9.1 Adults With Physical Disabilities**

A focus group was conducted with individuals with a physical disability in Kingston, Ontario. These discussions focused on two areas: the issues that consumers of services must address with the current systems of care, and how improvements can be made with the system.

Five individuals participated in the focus group with individuals with a physical disability. They ranged in age from their mid-20s to 50 years of age. They had a range of backgrounds that has led to their disability, ranging from a diving accident to an undiagnosed condition. Two of the participants chose not to state why they had a physical disability and confined to a wheelchair.

### **9.2 The Existing ‘Systems’**

Participants identified a number of issues surrounding the provision of services. One individual gave an example of changes in her own service mix. She had been receiving home support services from a municipality. At one point she required Occupational Therapy services from a CCAC. As a result, the municipality said she should be receiving her home support services also from the CCAC. Unfortunately the eligibility criteria are different for the CCAC and she was not eligible. Through a peer’s advice, however, she was able to receive some services from an Attendant Outreach program that was running in the community in which she lived. Otherwise, she would have had no support services available.

Participants commented on the fact that the ‘system’, as set up, discourages people with disabilities from seeking employment. At a certain income level services are cut off or reduced, which means that if they still require the services, and there is no reason to think otherwise, they will have to pay for these services out of their own pocket. There is then, a strong incentive to remain on income support, and very little incentive to seek employment.

‘Time’ is always a factor when accessing services or support. *“You’re always waiting for something”*, whether it be a service, treatment, application for financial support, getting a Van modified, or requesting changes around the home environment.

While respondents commented that it was good to have an Access Bus for transportation services, the bus does not meet the needs of many individuals. There is a 1-2 week waiting list to use the bus and there is limited flexibility in the hours in which it can be used. Another example of transportation problems was illustrated with the example of one person who had moved to another city for a new job and had arranged for Paratranspo services. That service went on strike, however, and until the strike was settled the individual had to pay \$40 dollars a day in taxi fare.

Another major concern was the nature of the services provided by community-based agencies. Some agencies will let their workers *“do a little bit more”*, while others will be strictly limited to the services listed to be provided. Participants commented that they had to train professional staff how to perform certain functions (e.g., catheterization). They felt that para-professional home

support staff could perform the task equally well and felt that it was not necessary for a nurse to be present when this was done.

One individual observed that when a new home care provider agency began services he “*got a new person every day ... that went on for months ... I had to train someone very day! It’s nice not to have to explain your routine all the time*”. Other participants agreed that they too are frustrated when new workers are always coming to their homes. At the time of the focus group one participant did not know if she was going to have someone available in the next day or who that even was – this is one of the uncertainties that people with disabilities often live with.

Another service issue was the time of day in which care was required. Typically these times are in the early morning and evening. But given the limited pool of attendant care/home support workers, there are often shortages and difficulties for all clients receiving the care they require at the time they require it. Participants acknowledged that this was, in part, due to the nature of the job – there is a high turnover of staff, they noted, due to the low wages and the desire for more job stability in institutional settings

Simple access issues taken for granted by those without disabilities were raised. One participant, for example, commented that she can not access the building her physician is in because of the steps. She does not want to be carried in and has on occasion met the physician in her Van. Parking meters are sometimes too high, or away from the curb, or the height of the curb itself is too high to maneuver a wheelchair. If it is raining then many individuals with wheelchairs are reluctant to access services. The point is that there are a number of access issues that people with disabilities must deal with even in addition to the navigation and frustration of using multiple service providers.

There was unanimous support for the Self-managed Attendant Services – Direct funding program funded by the Ontario Ministry of Health and run through the Centre for Independent Living in Toronto (CILT). Attendants in this program assist with routine activities of daily living (e.g., personal care, dressing, transferring, housekeeping, meal preparation, shopping) and are employed by the person with the disability. Up to 182 hours of care can be provided, the precise number determined after the individual has submitted an application outlining the type and extent of specific care needs required.

Typically up to 6 hours a day of support is provided. Funding is provided to hire a bookkeeper and the program also provides a pager if an attendant is required to be on call. The program, and others like it across the country, is very popular and successful, in part because it provides a strong degree of control for individuals and makes the service system ‘*client driven*’ as opposed to client centered or system driven. The same worker is available and the selection of the worker is determined by the person with the disability. Participants commented that it was hard to access the program, and is not always the best option for some people, but at the same time they saw enormous potential for an expanded program, that they felt would be cost-effective, appropriate to their care needs, and retained elements of choice, flexibility, dignity and respect that are often absent from traditional modes of service delivery.

### 9.3 Improvements in the Systems

Participants commented that improvements in the systems of care could be made through greater client control (client driven approach), less bureaucracy (and duplication) and a greater say by people with disabilities in how services are provided. They felt also that there is too much policy regulation at higher levels that restrict the degree of flexibility of support workers in being able to respond to the care needs of the individual. Participants also expressed a huge need for expanded and improved forms of supportive housing that addressed the needs of those with disabilities. There are three-year waiting lists, for example, for some housing supports in the community for those with disabilities.

Improvements would also be enabled through a heightened awareness by providers, policymakers and the general public of the issues which those with disabilities must address. Transportation services need to be expanded and improved, and public places need to be more accessible.

### 9.4 Family Caregiver Perspectives

Concerns from family caregivers ranged from the ability to access services for a spouse of son/daughter, to the ability of the caregiver to cope with very trying circumstances.

A major concern expressed was the bureaucracy around accessing services – *“The red tape is outrageous”*. *“You have to wait one year for services [OT/PT], and 6 months to be assessed for a wheelchair! I find that really really sad...”*

What makes the service accessibility issue more problematic is that, as with other provinces, children’s services are considerably better. But with the transition to adult services a ‘big gap’ emerges in the extent of services available. Ironically, noted one mother, this is the age group that requires independence more than ever, which is part of what the supports are intended to achieve. And while children often have the services brought to them, adults are more likely to have to go to the services.

A major concern for parents is the point at which they decide that they have little option but to seek placement for their child (young adult). As one mother described it, these are middle-aged parents who have been caring for their child for 20-25 years and feel, for a variety of reasons, that it may be time for their child (but could also be a spouse) to be placed in a home of some sort. But then there is a shortage of Group Homes, and considerable pressure felt that they should not seek placement for their family member. The reality, however, is that if services are being reduced, and there are shortages of group homes or other living arrangements, there is growing stress on the family as a whole.

One mother asserted that the government *“must put more money into the system. If you take away the institution then fine, but put the money back into the community. If there was an institution there would be parents who would put their children there – they can’t cope any more!”*

Improvements in the systems of care centered around the need for government to fund families and not the organizations providing the care. Again, this would instill greater levels of independence and control for clients and families. Improved levels, or even availability of respite services, is also required. Overall, several insightful comments reflect the basis upon which changes in the systems of care could be made:

*“You have no choice, the choices are not there”*

*“It all comes down to individual funding, you have the money, you buy the service”*

*“It’s difficult for people to get off the system because services will get taken away”*

*“People with disabilities should not be seen as welfare cases but they are. They should have a decent pension. It’s not their choice to be disabled.”*

*“As a society we have to make sure these people live with dignity and support. We have a responsibility.”*

## **9.5 Summary**

It was clear from the discussions with individuals dealing with the systems of care on a daily basis that there is still much to be done for adults with physical disabilities. Service provision in the home is critical and access to transportation is essential. The predominant views are that clients should have greater control over what and how services are provided. This would enhance flexibility, choice, respect and dignity.

## 10. DISCUSSION

The scope of the involvement of several departments and services for a truly integrated system of care for the physically disabled population was viewed as a challenge. Both government and community respondents recognized the critical issue of case management and assistance with navigating the system, not just within the continuing care system but particularly across broader health, social and other sectors. For persons with disabilities their need for income assistance, social services, health care, housing, employment and training or vocational services may be located in separate departments and the policies can be occasionally in conflict with one another. These differences must be resolved if a responsive system is to be established.

Both government and community-based advocacy organizations discussed the importance of changing the community's attitudes. Government officials focused on this in terms of creating an inclusive community, and the advocacy groups in terms of focusing on the capacities of the individual.

The need for greater focus on the broad determinants of health and emphasis on social model was highlighted throughout the interviews. Particularly noteworthy was the need for greater resources at the "*lighter end*" of the continuum of care to help create capacity and reduce the individual's dependency on more intensive services (e.g., promote vocational skills and independent living to reduce the likelihood of living in a long term care facilities later).

Inadequate funding, limited capacity, and regional differences clearly indicate that while there are a range of services available in every jurisdiction, there truly exists a two-tiered system where those who can afford to pay for private service can access more options than those who either can only access limited public services or those who, because they are just above the eligibility criterion, have to do without much of anything as they cannot afford to purchase services. Not surprisingly, there was consensus that the glaring gaps were in those very areas that maintain people in the community and sustain health and well-being – notably housing, rehabilitation, equipment, home support, adult day, respite, crisis support, medications. These areas are the most lacking and illustrate great inequities. Community organizations play a major role in the health care system, a role that many feel is under-recognized and undervalued by the public sector.

From the interviews conducted across the country and with a diverse range of stakeholders, it appeared that there are a number of essential services and supports for adults with physical disabilities that should be in place to respond effectively to the on-going and sometimes fluctuating needs of clients.

The following set of services is by no means definitive. It is based on the views of interview respondents and builds upon the list of services described in Appendix Three. The overriding theme of the list, however, is to focus on an individuals' client independence in the community.

## **Essential services and supports for adults with physical disabilities**

**Acute care needs** – Access to specialist services (timely, physical and financial ease of access)

### **Community-based support –**

- Self-managed attendant services
- Attendant services
- Homemaker services
- Care coordination
- Home care nursing
- Community physiotherapy and occupational therapy
- Technical aids, equipment and supplies
- Transportation services
- Supportive housing
- Life and social skills for independent living
- Income assistance
- Vocational support
- Respite for family caregivers, if required.

**Long term care (facility-based) needs** – Access to respite beds (for caregivers if necessary), congregate living residences (when and if necessary)

There are many other services that facilitate access to care and support for adults with physical disabilities. These include enhanced information awareness and communication, support groups, and crisis support. Knowing ‘where to turn’, and how best to do it is essential to the effective and appropriate support for adults with physical disabilities.

## 11. CONCLUDING COMMENTS

Within the broad determinants of health many sectors contribute to the health and well-being of adults with physical disabilities. The findings from this study make it clear that community-based services must be developed and enhanced for adults with disabilities. An adequate income level is essential to enable the appropriate level of services to be provided while at the same time creating incentives to be more fully integrated into society without the concerns of losing income supports. The distinct lack of equipment and the removal from public funds of supplies for persons with disabilities creates a disproportionate burden on this population. There is also a huge gap in rehabilitation services – wait-lists, shortages of staff, and rural-urban inequities, that must be addressed.

Integration based on a social model of care can go a long way to addressing these issues. Integration of services is essential because of the wide array of service sectors providing care and support to those with disabilities. Independence in the community requires that community supports be integrated *around the support needs of the individual*, in which case there is considerable merit in the underlying approaches to individualized funding models whereby the client not only is at the centre of services but, where appropriate, also controls the array of services; when they are provided, for how long and by whom.

The study also emphasizes that people (family and formal caregivers) are equally important if not moreso than the formal systems of care. The advocate/navigator is critical to the care of the individual. Preventive care plays a major role for individuals as do home support services and any other programs that facilitate independence. Greater levels of integration would also be enhanced by reducing the extent of variation in service availability and accessibility both within and among provinces and regions. Programs and services to facilitate independence must be developed which recognize the various strands of supports that each person with a disability must integrate into their lives on a daily basis. Governments and provider organizations need to play lead roles in concert with persons with disabilities to provide services that avoid confusion and duplication and that can be tailored to suit the often complex and varying needs of persons with disabilities.

Disability supports assist an individual with a disability to overcome any barriers to his or her participation in the economic and social life of their community. Although there is a need for the community itself to provide the enabling features for this to occur, there is also a need for individuals with disabilities themselves to be their own ‘self-advocates’. In other words, they themselves know what their needs are and the potential array of supports required to address those needs. The effective integration of services, therefore, must be broadened to reflect this additional interface of the individual’s knowledge and the availability of supports.

Recognizing the uniqueness of individuals with a disability, an integrated system of care will also not be effective if it does not incorporate both philosophically and practically the fundamental tenets emanating from the recent *In Unison* documents. Integration and coordination will not be effective for persons with disabilities without full lines of accountability, portability, shared responsibility, individual control, entitlement and the desire and need for independence being firmly established in policy and practice. Indeed, as the *In Unison 2000*

document observes, “*There is much that remains to be done to achieve full citizenship for people with disabilities. Governments recognize that achieving this vision will require all sectors in society to work together in developing a range of solutions. Full inclusion cannot be achieved overnight, nor by the efforts of any one government or agency. Governments understand the importance of setting priorities and moving ahead step-by-step to build on the progress that has already been made.*”

The literature on health integration is very limited with regard to services for persons with disabilities. It is clear that there is a growing recognition that integration, or rather effective coordination, is of vital importance to persons with disabilities. Their needs have yet to be articulated in the emerging body of literature on health integration, even though some of the underlying issues and approaches could enrich the discussion on health integration considerably (e.g., the role of the social model, individual control of care, and the need to accommodate the uniqueness of the disability and the required supports for every person with a disability).

There was a clear sense from the stakeholders interviewed in this study that it is well known what is required for more effective supports to be put in place. Indeed, the stakeholder comments echoed the ‘Canadian approach’ to disabilities in the *In Unison* documents. The challenge is to build on the momentum of the *In Unison* work and to ensure that policymakers, providers and the general public see the merit in enhancing the services to this population. There needs to be a coalescence of thought and decision-making between the sectors that provide formal programs and services to persons with physical disabilities, and the health care sector could play a lead role if, indeed, it is essential that one sector takes a lead over another. The sectoral focus on the delivery of services, in fact, may soon be outdated as the focus of supports becomes more tightly woven around the many and diverse needs of different individuals. At the same time, it is challenging to do this in a period when conventional ‘systems of care’ are faced with growing fiscal and demand pressures. Community-based care especially, has faced numerous cuts to funding and services, and yet it is in the community that the full citizenship of persons with disabilities is required.

This study has emphasized a need for further research on the issues, but at a detailed level whereby many system features for integration could be examined to fully understand what works and what does not at the micro and meso levels (i.e., client-provider interface and in regional health authorities). These considerations should embrace the knowledge that the ‘ideal system’ appears to work best at an individual level, and conceptually, ‘around’ each individual, differently depending on their unique needs. That is why self-managed care and individualized funding programs make considerable philosophical and practical sense.

Finally, further research could also focus on issues such as an examination of an individual’s array of services over time, the extent of coordination within a regional health authority, the effects of inter-ministerial cooperation, examination of portability within and amongst regional health authorities and a review of Best Practices for integration of services for adults with physical disabilities. The lessons learned from these studies will greatly enhance our level of understanding as it is the unit of analysis most noticeably absent in both the literature on integration and service system provision for persons with disabilities.

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## **Appendix 1: Interviews Conducted With the Following Stakeholders**

### **ALBERTA**

Long Term Care Centre, Edmonton  
Carewest, Calgary  
Alberta Committee of Citizens with Disabilities  
Premier's Council on Disabilities  
Alberta Association for the Handicapped  
Handicapped Housing

### **BRITISH COLUMBIA**

BC Coalition of People with Disabilities  
BC Lung Association, British Columbia  
CACL  
ALS Society  
Parkinsons Society  
Government, Office for Disability Issues  
Multiple Sclerosis Society

### **MANITOBA**

Government of Manitoba  
DAWN Canada  
University of Winnipeg  
League of People with Disabilities  
Consumer

### **NEW BRUNSWICK**

NB Family and Community Service (2 respondents)  
Extramural Region NB  
Easter Seal March of Dimes  
Stroke Recovery Program – Saint John Regional Hospital  
Southeast Deaf

### **NEWFOUNDLAND**

Residential Service NFLD Health and Community Services  
Health & Community Services Continuing Care, St. John's Region  
Newfoundland Society for Physically Disabled  
Hoyles Escasoni

### **NORTHWEST TERRITORIES**

NWT Council for Disabled Persons  
Inuvik LTC Facility  
YWCA, Yellowknife  
NWT Government

**NOVA SCOTIA**

NS Department of Community Services  
NS Disabled Persons Commission  
Cumberland Abilities Partnership Association  
Canadian Paraplegic Association  
QEII HSC-NS Rehabilitation  
NS DEPT OF HEALTH - Home Care

**NUNAVUT**

Government of Nunavut

**ONTARIO**

Kingston Independent Living Resource Centre  
Extend-A-Family  
Thalidomide Victims Association of Canada

**PEI**

Disabled Division Dept of Health and Social Services  
PEI Council of Disabled  
Kay Reynolds Centre, PEI  
Continuing Care, Queens Health Region

**QUEBEC**

Conseil de la santé et du bien-être  
Office of the Handicapped  
CLSC (1), Quebec  
CLSC (2), Quebec  
CLSC (3), Quebec

**SASKATCHEWAN**

Office of Disability Issues, Saskatchewan Social Services  
Regina Health District  
Lloydminster Health District  
Saskatchewan association of Rehabilitation Centres  
South Saskatchewan Independent Living Centre  
Saskatchewan Voice of People with Disabilities  
Regina and District Association for Community Living  
SARCAN

**YUKON**

Yukon Government, Health and Social Services, Adult Services  
Provider Agency

## **Appendix 2: Project Summary**

### **ANALYSIS OF INTERFACES ALONG THE CONTINUUM OF CARE**

Federal, Provincial and Territorial Ministries of Health, and Health and Social Services, have expressed a need to have more information about issues related to what makes for an integrated continuum, or system, of care delivery for a number of population groups including seniors, adults with disabilities, adults with mental health concerns, and children. Health Canada has recently funded Hollander Analytical Services in Victoria, B.C. to oversee the Analysis of Interfaces Along the Continuum of Care study which will examine this issue directly.

The study is being conducted by four teams. Each team will be responsible for collecting information on care delivery for one of the specified populations from across Canada. Input will be sought from policy/decision makers (e.g. federal/provincial/territorial officials) as well as individuals who are affected by the services (e.g. service providers, consumer groups).

Study information will be collected using phone surveys and focus groups. The phone interviews will take approximately one hour. They will look at what the commonly used health related services are for the population of interest, how well these services are integrated into a system of service delivery, how well they are linked to other parts of the health system, and how well they are linked to services outside of the health system. We will also ask respondents what they think makes an effective system of service delivery, what they see as blockages or impediments to an effective system of service delivery, and what suggestions they may have for improving the system of service delivery. The focus groups will take one to two hours. They will obtain information from consumers, families, and consumer groups regarding service delivery. Each team will conduct approximately 80 phone interviews and two focus groups.

Participation in the study is completely voluntary and each person has the right to refuse to participate. Respondents may also refuse to answer any questions during the study. They may also withdraw at any time, without explanation. All responses will be confidential. No information that could identify individual respondents will be reported.

The final report, which is scheduled to be completed by August 1, will include findings on each of the populations under investigation. It will also contain an analysis of the findings which will include: new or reformulated conceptual models; in depth discussion of the blockages to effective service delivery and the opportunities for more integrated care provision; and analysis of the transferability or commonality of findings across jurisdictions. The results of the study will provide federal, provincial, and territorial decision makers with the evidence they need to improve the way health services are organized and delivered across Canada.

## **RÉSUMÉ DU PROJET D'ANALYSE DES INTERFACES DU CONTINUUM DES SOINS DE SANTÉ**

Les ministères provinciaux, territoriaux et fédéral de la santé et des services sociaux ont dit vouloir obtenir davantage de renseignements sur la façon d'unifier un continuum ou un système de soins de santé destiné à un certain nombre de groupes démographiques, dont les aînés, les adultes handicapés, les adultes ayant des problèmes de santé mentale et les enfants. Santé Canada a récemment accordé du financement à la société Hollander Analytical Services, située à Victoria, en Colombie-Britannique, afin qu'elle supervise l'Analyse des interfaces du continuum des soins de santé qui abordera directement cette question.

Quatre équipes se chargent de l'étude. Chacune a la responsabilité de recueillir des renseignements concernant la prestation, partout au pays, de soins de santé à l'un des groupes démographiques mentionnés. On demandera l'opinion de décideurs et de responsables des politiques (p. ex., les responsables des gouvernements provinciaux, territoriaux et fédéral), ainsi que des personnes touchées par les services (p. ex., les fournisseurs de services et les groupes de consommateurs).

On effectuera des sondages téléphoniques et on mettra sur pieds des groupes de discussion afin de recueillir les renseignements qui serviront aux fins de l'étude. Les entrevues téléphoniques dureront environ une heure. Elles nous permettront de savoir quels sont, pour les personnes cibles, les services de santé les plus souvent utilisés, à quel point ces services sont intégrés à un système de prestation de services, à quel point ils sont liés aux autres éléments du système de santé, et à quel point ils sont liés à des services extérieurs au système de santé. Nous demanderons aussi aux personnes qui répondront au sondage ce qui, à leur avis, permet à un système de prestation des services d'être efficace, ce qui pourrait constituer un obstacle à l'efficacité du système de prestations de services, et ce qui pourrait améliorer le système de prestations de services. Les réunions des groupes de discussion dureront d'une à deux heures. Elles permettront d'obtenir l'opinion des clients, des familles et des groupes de consommateurs au sujet de la prestation de services. Chaque équipe effectuera environ 80 entrevues téléphoniques et mettra sur pied deux groupes de discussion. La participation à l'étude est entièrement volontaire et chaque personne peut refuser de participer. Les participants peuvent aussi refuser de répondre à toute question au cours de l'étude. De plus, ils peuvent abandonner à tout moment sans fournir d'explication. Toutes les réponses resteront confidentielles. Aucun renseignement concernant les personnes qui auront participé ne sera divulgué.

Le rapport final, qui devrait être terminé d'ici le 1<sup>er</sup> août, comprendra les conclusions au sujet de chacun des groupes à l'étude. Il fournira aussi une analyse des conclusions et inclura les modèles conceptuels nouveaux ou reformulés, une analyse détaillée des éléments qui nuisent à l'efficacité de la prestation des services et à la possibilité de fournir des soins de santé plus unifiés, ainsi qu'une analyse de la transférabilité ou de la mise en commun des conclusions entre les différentes compétences. Les résultats de l'étude fourniront aux décideurs des gouvernements provinciaux, territoriaux et fédéral les éléments dont ils ont besoin pour améliorer l'organisation et la prestation des services de santé partout au Canada.

### Appendix 3: List of Services

#### Telephone List of services to Adults with Disabilities

Your name:

Organization:

#### List of Services, and Definitions, Adults with Disabilities

Commonly used Services	Publicly Funded Services				Comments
	1) Yes	2) No	3) Mix	3) Should be	
<b>Home and Community Services</b>					
<b>Self-managed Attendant Services</b> offers funds based on assessed need to the individual for the purpose of organizing his/her own care. Decisions about whom to hire, the level and type of service needed are those of the individual.					
<b>Attendant services</b> are available on a regular basis for persons with disabilities to assist with ADLs and IADLs.					
<b>Assessment and Case Management</b> constitutes a process of screening clients, conducting assessments, determining care needs, determining eligibility, making referrals to appropriate services, admitting clients into service(s) and providing for the ongoing monitoring of care requirements, including the revision of care plans, and discharge planning. Assessors/Case Managers may also conduct financial assessments, act as client advocates in facilitating care provision and manage facility waiting lists.					
<b>Meal Programs</b> are generally voluntary community services that deliver a nutritious hot, or frozen, meal to the homebound client (Meals-on-Wheels) or bring the client to a congregate setting to have a meal (Wheels-to-Meals). The goal of Meal Programs is to supplement a client=s diet by delivering an attractive nourishing meal to help maintain or improve health. Governments may pay for some of the costs of this program, e.g., cost of meals, transportation subsidy.					

Commonly used Services	Publicly Funded Services				Comments
	1) Yes	2) No	3) Mix	3) Should be	
<p><b>Homemaker Services</b> are provided to clients who require non-professional (lay) personal assistance with care needs or with essential housekeeping tasks. Personal care needs may include help with dressing, bathing, grooming, and transferring, whereas housekeeping tasks might include activities such as cleaning, laundry, meal preparation, and other household tasks. Homemakers may have post secondary training to the same level as Aids and Care Attendants and may provide similar types of personal care services. Specific nursing and rehabilitation tasks may also be delegated to Homemakers. Homemaking can also be provided as a respite service.</p>					
<p><b>Home Care Nursing</b> provides comprehensive nursing care to people in their homes, generally by registered or psychiatric nurses. A home care nursing program coordinates a continuum of nursing services designed to support clients of all ages to remain in their homes during an acute, chronic, or terminal illness. This community based program provides nursing care in the client=s own environment. Home care nursing encourages clients and their families to be responsible for, and to actively participate in, their own care. Thus, teaching and self-care are promoted. Goals for home care nursing can be curative, rehabilitative, palliative, or supportive.</p>					
<p><b>Community Physiotherapy and Occupational Therapy</b> provide direct assessment, treatment, consultative and preventative services to clients in their homes to monitor, rehabilitate, or augment function, or to relieve pain. Therapists may also arrange for the necessary equipment to manage the clients= physical disabilities and may train family members to assist clients. Community physiotherapy and occupational therapy programs also may provide consultative, follow-up, maintenance, and educational services to clients, families, physicians, other health providers, hospitals, and Long Term Care facilities.</p>					

Commonly used Services	Publicly Funded Services				Comments
	1) Yes	2) No	3) Mix	3) Should be	
<p><b>Adult Day Support</b> provides personal assistance, supervision and an organized program of health, social, educational and recreational activities in a supportive group setting. Nursing, rehabilitation, and a range of other professional and ancillary services may be provided. The program is designed to maintain persons with physical and/or mental disabilities, or restore them to their optimum capacity for self-care. It can also be used to provide respite care, training and informal support to family caregivers. Adult Day Support may be provided within a residential care facility or may be provided through organizations in the community.</p>					
<p><b>Group Homes</b> are homes or home-like residences which enable persons with physical and/or mental disabilities to increase their level of independence through a pooling of group resources. They must be able to participate in a cooperative living situation with other challenged individuals. This type of care is particularly suited for disabled young adults who are working, enrolled in an educational program, or attending a sheltered workshop. It may also be provided to seniors and others who require an alternative to facility care.</p>					
<p><b>Residential Services</b></p>					
<p><b>Long Term Care Facilities</b> provide care for clients who can no longer live safely at home. Residential care services provide a safe, protective, supportive environment and assistance with activities of daily living for clients who cannot remain at home due to their need for medication supervision, 24-hour surveillance, assisted meal service, professional nursing care and/or supervision. Clients may have moderate to heavy care needs which can no longer be safely or consistently delivered in the community. They may suffer from a chronic disease, from a disability that reduces their independence and, generally, can not be adequately cared for in their homes. In some cases, all facility services, including chronic care, are provided in Long Term Care facilities.</p>					

Commonly used Services	Publicly Funded Services				Comments
	1) Yes	2) No	3) Mix	3) Should be	
<p><b>Chronic Care Units/Hospitals</b> provide care to persons who, because of chronic illness and marked functional disability, require long term institutional care but do not require all of the resources of an acute, rehabilitation or psychiatric hospital. Twenty-four hour coverage by professional nursing staff and on-call physicians is provided, as well as care by professional staff from a variety of other health and social specialities. Only people who have been properly assessed and who are under a physician=s care are admitted to chronic care facilities. Care may be provided in designated Chronic Care Units in acute care hospitals or in stand alone Chronic Care Hospitals. Care requirements are typically 2.5 hours of professional nursing care per day or more.</p>					
<p><b>Assessment and Treatment Centres and Day Hospitals</b> provide short-term diagnostic, assessment and treatment services in a special unit within an acute care hospital or other health facility. These centres provide intensive short term assessment services to ensure that persons with complex physical mental and social needs are correctly assessed, diagnosed, and treated. The objective of the centres is to assist the client to achieve, regain, and maintain an optimal level of functioning and independence. Centres may have beds for short-term inpatient assessment and treatment, a day hospital service, and/or an outreach capability which permits staff to assist clients, who are in care facilities or in their homes, and their families.</p>					
<p><b>Education and Employment Services</b></p>					
<p><b>Vocational Sevices</b> refer to rehabilitation training services including tutors and interpretors</p>					
<p><b>Employment Outreach Programs</b></p>					

Commonly used Services	Publicly Funded Services				Comments
	1) Yes	2) No	3) Mix	3) Should be	
<b>Additional Services Often Included in Continuing Care</b>					
<b>Technical aids, Equipment and Supplies</b> may be provided as required to maintain a person=s health, e.g., medical gases or assisted-breathing apparatus, and to improve the opportunities for self-care and a better quality of life, e.g., wheelchairs, walkers, electronic aids, etc. Equipment may be loaned, purchased or donated.					
<b>Transportation Services</b> may be provided to persons with disabilities and others with mobility related limitations to allow them to go shopping, keep appointments and attend social functions. Some vehicles are adapted for wheelchairs and other devices.					
<b>Information services</b> refer to publicized, readily available and accessible (in multiple formats) information as a guide for persons in finding out what is available to them with relevant eligibilty criteria.					
<b>Support Groups</b> may be initiated by many sources, e.g., community and institutional health services, friends, families of clients, and individuals having similar needs. The groups provide peer support and foster mutual aid. Some groups may receive government subsidies.					
<b>Crisis Support</b> may be available in the community to give emergency assistance when existing arrangements break down, e.g., illness of the spouse or caring for a disabled person, which could include facilitation of emergency admission to institutional care, or the provision of enhanced Home Care.					
<b>Life and Social Skills for Independent Living</b> may provide training and support for independent living, and for social and personal development and integration, in group settings or on an individual basis.					
<b>Respite Services</b> may be provided to primary caregivers to give them temporary relief or support by providing a substitute for the caregiver in the home or by providing alternate accommodation to the client in a residential setting.					

Commonly used Services	Publicly Funded Services				Comments
	1) Yes	2) No	3) Mix	3) Should be	
<b>Palliative Care</b> is an interdisciplinary service that provides active, compassionate care to the terminally ill in their home, a hospital, or other health care facility. Palliative care is provided to individuals, and their families, where it has been determined that treatment to prolong life is no longer the primary objective.					
<b>Volunteers</b> may provide programs of volunteer help that are utilized in addition to formal care services. Volunteer services may include, but are not limited to, friendly visiting, telephone reassurance and monitoring, doing errands and shopping, and other social and recreational activities.					
<b>Social Housing</b> includes affordable, centrally located housing with appropriate modifications to support independent function.					
<b>Congregate Living Residences</b> are apartment complexes which offer amenities such as emergency response, social support and shared meals.					
<b>Income assistance</b> may be provided through federal programs, such as disability tax credits or income from disability benefits and provincial programs such as Workman=s Compensation Board which is provincial delivery of employer funded income replacement program, Family Benefits or social assistance.					
Other, specify:					
Other, specify:					
Other, specify:					

## Liste téléphonique — Services offerts aux personnes handicapées

Votre nom :

Organisme :

## Liste des services et définitions — Personnes handicapées

Services les plus utilisés	Services financés par l'État				Commentaires
	1) Oui	2) Non	3) En partie	4) Devraient l'être	
<b>Services communautaires et à domicile</b>					
Les <b>services auxiliaires autogérés</b> offrent du financement à la personne handicapée en fonction de l'évaluation de ses besoins. L'argent doit lui permettre de s'occuper de ses propres soins. Elle choisit elle-même qui elle veut embaucher ainsi que le type et le degré de soins dont elle a besoin.					
Les <b>services auxiliaires</b> sont offerts aux personnes handicapées de façon régulière afin de leur permettre de vaquer à leurs activités quotidiennes et à leurs activités instrumentales quotidiennes.					
<b>L'évaluation et la gestion des cas</b> constituent un processus qui a pour objet la sélection des bénéficiaires, l'évaluation des cas, la détermination des besoins en matière de soins, la détermination de l'admissibilité des bénéficiaires, l'orientation vers les services appropriés, l'admission des bénéficiaires à un service, le suivi des soins requis, y compris la modification des plans de soins, et la planification des congés. Les évaluateurs ou les responsables de cas peuvent aussi effectuer des évaluations de la situation financière des bénéficiaires, agir comme représentants des bénéficiaires pour faciliter l'obtention de services et gérer les listes d'attente pour l'admission à un établissement.					

Services les plus utilisés	Services financés par l'État				Commentaires
	1) Oui	2) Non	3) En partie	4) Devraient l'être	
<p>Les <b>programmes de repas</b> sont un service communautaire généralement bénévole qui a pour but de livrer des repas nutritifs, chauds ou congelés, aux bénéficiaires confinés à domicile (Meals-on-Wheels) ou de transporter les bénéficiaires à une salle à manger communautaire où ils pourront prendre un repas (Wheels-to-Meals). L'objectif de ces programmes (souvent appelés <i>popote roulante</i>) est de compléter le régime alimentaire du bénéficiaire en lui offrant des plats appétissants et nourrissants qui lui permettent de maintenir ou d'améliorer son état de santé. Les gouvernements peuvent assumer une partie des coûts de ces programmes, p. ex. le coût des repas ou les frais de transport.</p>					
<p>Les <b>services d'aide familiale</b> sont dispensés aux bénéficiaires qui ont besoin d'une aide non professionnelle en matière de soins personnels ou de tâches ménagères essentielles. Par soins personnels, on entend l'aide fournie aux personnes pour se vêtir, prendre leur bain, faire leur toilette et se déplacer, tandis que les tâches ménagères comprennent le ménage, la lessive, la préparation des repas et d'autres activités d'entretien ménager. Les aides familiales peuvent avoir une formation postsecondaire équivalente à celle des préposés aux soins et fournir des soins personnels similaires. Certains soins infirmiers et services de réadaptation peuvent aussi être dispensés par les aides familiales. Les services d'aide familiale sont parfois offerts comme service de relève.</p>					
<p>Les <b>soins infirmiers à domicile</b> permettent aux bénéficiaires de recevoir, à leur domicile, un éventail complet de soins infirmiers, habituellement dispensés par des infirmières, généralistes ou psychiatriques. Ce programme assure la coordination des services infirmiers qui aideront les bénéficiaires de tous âges à demeurer à la maison même s'ils souffrent d'une maladie aiguë, chronique ou en phase terminale. Ce programme communautaire fournit au bénéficiaire des soins infirmiers dans son propre environnement. Il encourage les bénéficiaires et leur famille à participer activement aux soins; il comporte donc un volet éducation et prise en charge. Les soins peuvent être d'ordre curatif ou palliatif ou viser la réadaptation ou le réconfort du patient.</p>					

Services les plus utilisés	Services financés par l'État				Commentaires
	1) Oui	2) Non	3) En partie	4) Devraient l'être	
<p>Les <b>services communautaires de physiothérapie et d'ergothérapie</b> procurent des services d'évaluation, de traitement, de consultation et de prévention au domicile des bénéficiaires, afin de vérifier, de rétablir ou d'accroître leur fonctionnement, ou de soulager leur douleur. Les thérapeutes peuvent aussi faciliter l'obtention de l'équipement requis par les handicapés physiques et apprendre aux membres de la famille à prendre soin du patient. Les programmes communautaires de physiothérapie et d'ergothérapie offrent habituellement des services de consultation, de suivi, de maintien et d'éducation aux patients, aux familles, aux médecins et autres professionnels de la santé, aux hôpitaux et aux établissements de soins de longue durée.</p>					
<p>Les <b>centres de jour pour adultes</b> fournissent une aide personnelle, de la supervision et un programme structuré d'activités sanitaires, sociales, éducatives et récréatives dans un contexte communautaire protégé. Des soins infirmiers et de réadaptation ainsi qu'un ensemble d'autres services professionnels et auxiliaires peuvent être offerts. Le programme vise à assurer le maintien des handicapés physiques ou mentaux ou à rétablir le plus possible leur capacité personnelle de prendre soin d'eux-mêmes. Il peut aussi fournir des services de relève, de formation et de soutien informel à la famille. Les centres de jour pour adultes peuvent être situés dans un établissement de soins ou être offerts par des organismes communautaires.</p>					
<p>Les <b>foyers de groupe</b> sont des foyers ou des résidences privées qui permettent aux handicapés physiques ou mentaux d'accroître leur autonomie en partageant des ressources communes. Ces personnes doivent être capables de vivre en commun avec d'autres personnes ayant des besoins spéciaux. Ce type de service convient particulièrement aux jeunes adultes handicapés qui travaillent, qui participent à un programme d'éducation ou qui fréquentent un atelier protégé. Il s'adresse également aux personnes âgées et aux personnes pour qui on recherche une solution autre que l'admission dans un établissement.</p>					

Services les plus utilisés	Services financés par l'État				Commentaires
	1) Oui	2) Non	3) En partie	4) Devraient l'être	
Services offerts en établissement					
<p>Les <b>établissements de soins de longue durée</b> prennent en charge les personnes qui ne peuvent plus vivre à la maison sans mettre leur sécurité en péril. Ces établissements procurent un environnement protégé ainsi que des services de soutien et d'aide pour les activités de la vie quotidienne aux personnes qui ne peuvent rester à la maison parce que leur médication doit être surveillée ou qu'elles nécessitent une surveillance continue, de l'aide pour s'alimenter, des soins infirmiers ou une supervision professionnelle. Les soins requis par les bénéficiaires peuvent être modérés ou assez lourds, et ne peuvent plus être dispensés de façon sécuritaire ou régulière par les services communautaires. Les bénéficiaires peuvent souffrir d'une maladie chronique ou d'un handicap qui réduit leur autonomie et, en général, ils ne peuvent plus être soignés adéquatement à leur domicile. Dans certains cas, tous les services en établissement, y compris les soins aux malades chroniques, sont dispensés dans les établissements de soins de longue durée.</p>					
<p>Les <b>unités/hôpitaux de malades chroniques</b> dispensent des soins aux personnes qui, en raison d'une maladie chronique ou d'un handicap fonctionnel lourd, nécessitent une hospitalisation à long terme, mais n'ont pas besoin de toutes les ressources d'un hôpital offrant des soins actifs, des services de réadaptation ou des soins psychiatriques. Les soins sont donnés 24 heures sur 24 par le personnel infirmier et des médecins sur appel ainsi que par d'autres professionnels de la santé et des services sociaux. Seules les personnes qui ont été adéquatement évaluées et qui sont traitées par un médecin peuvent être admises dans un établissement pour malades chroniques, qui est soit une unité de malades chroniques au sein d'un hôpital de soins actifs, soit un hôpital accueillant exclusivement des malades chroniques. On y dispense en général au moins 2,5 heures de soins infirmiers par jour.</p>					

Services les plus utilisés	Services financés par l'État				Commentaires
	1) Oui	2) Non	3) En partie	4) Devraient l'être	
Les <b>centres d'évaluation et de traitement et hôpitaux de jour</b> fournissent des services de diagnostic, d'évaluation et de traitement de courte durée au sein d'une unité spéciale d'un hôpital de soins actifs ou d'un autre établissement de santé. Ces centres offrent des services d'évaluation intensive qui visent à ce que les personnes ayant des besoins complexes sur le plan physique, social et psychiatrique soient correctement évaluées, diagnostiquées et traitées. Ils ont pour objectif d'aider les bénéficiaires à atteindre, à retrouver ou à maintenir un niveau maximal de fonctionnement et d'autonomie. Les centres peuvent compter des lits pour l'évaluation et le traitement de patients hospitalisés pour une courte durée, un hôpital de jour ou un programme d'extension des services qui permet au personnel d'aider les patients, qu'ils vivent en établissement ou à la maison, et leur famille.					
<b>Services d'enseignement et d'emploi</b>					
Les <b>services de formation professionnelle</b> offrent des services d'aide à la réadaptation par l'entremise, entre autres, de tuteurs et d'interprètes.					
<b>Programmes d'accès à l'emploi</b>					
<b>Services additionnels faisant habituellement partie des soins continus</b>					
De <b>l'équipement, du matériel et de l'aide technique</b> peuvent être offerts afin de maintenir l'état de santé des personnes qui ont besoin, par exemple, de gaz médicaux ou d'appareils d'assistance respiratoire, et d'accroître l'autonomie et la qualité de vie des personnes qui requièrent, par exemple, des fauteuils roulants, des marchettes ou des aides électroniques. L'équipement peut être loué, vendu ou donné.					
Les <b>services de transport</b> sont offerts aux personnes handicapées ou à mobilité réduite, qui peuvent ainsi faire leurs courses, aller à des rendez-vous et poursuivre leurs activités sociales. Certains véhicules sont adaptés pour les personnes se déplaçant en fauteuil roulant ou à l'aide d'autres appareils.					

Services les plus utilisés	Services financés par l'État				Commentaires
	1) Oui	2) Non	3) En partie	4) Devraient l'être	
Les <b>services d'information</b> renvoient à des renseignements publiés, accessibles (sous différentes formes) et actuellement offerts. Ces renseignements servent de guide et permettent aux personnes handicapées de savoir à quels services elles ont accès selon certains critères d'admissibilité.					
Les <b>groupes de soutien</b> peuvent être issus de nombreuses sources, p. ex. les services communautaires et les établissements de soins, les proches des bénéficiaires et des personnes ayant des besoins similaires. Ces groupes favorisent l'entraide et le soutien mutuel. Certains groupes peuvent être subventionnés par l'État.					
Le <b>soutien d'urgence</b> est parfois offert par les services communautaires pour assurer une aide immédiate aux personnes qui se retrouvent subitement démunies, p. ex. lorsque le conjoint d'une personne handicapée tombe malade, ce qui inclut les mesures prises pour faciliter l'admission d'urgence en établissement ou assurer la prestation de soins à domicile plus adéquats.					
Les <b>programmes de socialisation et d'apprentissage de la vie autonome</b> fournissent formation et soutien pour permettre aux personnes de mener une vie indépendante et les aider à se développer et à s'intégrer sur le plan social et personnel, dans un contexte collectif ou individuel.					
Les <b>services de relève</b> permettent d'offrir un répit ou un soutien temporaire aux soignants immédiats en leur procurant les services de remplaçants à domicile ou en fournissant un autre lieu d'hébergement au bénéficiaire, p. ex. dans un établissement de soins.					
Les <b>soins palliatifs</b> sont dispensés dans le cadre d'un service interdisciplinaire qui offre aux personnes atteintes d'une maladie en phase terminale des soins actifs et du réconfort, à domicile, à l'hôpital ou dans un autre établissement de santé. Les soins palliatifs sont donnés aux malades et à leur famille lorsqu'on détermine que les traitements visant à prolonger la vie du malade ne constituent plus l'objectif premier.					

Services les plus utilisés	Services financés par l'État				Commentaires
	1) Oui	2) Non	3) En partie	4) Devraient l'être	
Les <b>services bénévoles</b> sont offerts dans le cadre de programmes d'aide qui viennent compléter les soins officiels. Il englobent, entre autres, les visites amicales, les appels téléphoniques visant à rassurer et à surveiller les bénéficiaires, l'accompagnement pour les courses et l'organisation d'activités sociales et récréatives.					
Le <b>logement social</b> comprend des logements abordables et bien situés qui ont été modifiés afin de répondre à des besoins particuliers.					
Les <b>habitations collectives</b> sont des immeubles à logements qui offrent des services communs, tels que l'intervention d'urgence, le soutien social et des repas communautaires.					
L' <b>aide au revenu</b> peut être offerte par l'entremise de programmes fédéraux, comme le crédit d'impôt pour personne handicapée, sous forme de prestations d'invalidité, ou dans le cadre de programmes provinciaux, comme la Commission des accidents du travail, qui offre un programme provincial de remplacement du revenu financé par l'employeur, les prestations familiales ou l'aide sociale.					
Autre (préciser)					
Autre (préciser)					
Autre (préciser)					



# Appendix 4: Telephone Interview Schedule for the Analysis of Interfaces Along the Continuum of Care Project

## Specific to Adults with Disabilities

### PREAMBLE

Thank you for agreeing to participate in our survey, which is part of larger study funded by Health Canada. The results of this study will provide decision-makers with the evidence they need to improve the way health services are organized and delivered across Canada.

Federal, Provincial and Territorial Ministries of Health, and Health and Social Services, have expressed a need to have more information about issues related to what makes for an integrated continuum, or system, of care delivery for a number of population groups, including adults with disabilities.

The purpose of this study is to examine what makes for an integrated continuum, or system, of care delivery for a number of population groups, including seniors, adults with disabilities, adults with mental health concerns, and children.

### In this survey we wish to obtain your views about:

- § what are the essential, and/or most frequently used, health related services for adults with disabilities;
- § how well these services are currently integrated into a system of health care;
- § how well, or poorly, these services are linked to other parts of the health system (e.g., hospitals, physicians and community/public health);
- § how well they are linked to services outside of the health system, which may impact on adults with disabilities (e.g., social services, housing).

### We will also ask for your views about:

- What you think makes for an effective system of care;
- What blockages or impediments to effective, integrated systems of service delivery you see in the current arrangements, and;
- What suggestions you may have for improving the system of service delivery for adults with disabilities.

Please be assured that your responses will be treated in a **confidential manner**, that your participation in this survey is totally voluntary and that you can choose not to participate in the survey or not to answer any questions, at your discretion. May we proceed with the survey?

## **Background Information**

Your name:

Organization:

Province:

Region: \_\_\_\_\_

## ***Definitions:***

***Integration:*** The combining of several services into a set or system; the interaction among health services and services outside the health system. This implies that there are definable links and interdependencies.

***Interface:*** The ways and means that components of the health and non-health related services come together or interact with one another; sharing, softening, or touching of the boundaries or limits of service components.

***System:*** A set of services and the interactions between them. The components of a good-functioning system have the common goal of both meeting and integrating the health care needs of people with disabilities.

## ***SECTION 1***

### ***Questions Related to the System of Care for Adults with disabilities***

We have sent you a list of groups of services that may be used by adults with disabilities.

**1. Could you please indicate which of these services are currently essential and frequently used services by adults with disabilities in your jurisdiction? Please feel free to suggest other services if you feel the list is incomplete.**

*For services which you feel are not essential services at present, please indicate whether you feel that they should be core services in a fully integrated system of care for adults with disabilities, and why.*

**2. How do adults with disabilities typically enter the care delivery system?**

3. a) Within the range of services noted in Question 1, what:

- **facilitates** these services into a system of care for adults with disabilities?
- **hinders** the integration of these services into a system of care?

When identifying factors, some broad topic areas you may wish to consider are: clinical practice, communication within and between services, administration, evaluation, outcome and accountability, policy, finance and regional differences

b) To what extent are the services identified in Question 1 provided in the **most effective** manner (right setting/timing/provider)?

c) Has your jurisdiction developed **any recent initiatives** designed to improve integration? If so, how well have these initiatives worked?

4. Within the range of services provided to adults with disabilities noted in **question 1:**

- *Is it possible for funders or service providers to **move funding** from one type of service to another in response to client needs?*
- *To what extent does **money follow the client**, e.g., if more clients are looked after at home than in residential care are facility funds shifted to community care? Are there funding incentives for particular services?*

5. a) Within the range of services provided to adults with disabilities do you feel that there are **gaps** in the availability of these services? If so, could you please elaborate?

5.b) Within the range of services provided to adults with disabilities do you feel that there are existing services that are **under-utilized**? If so, could you please elaborate?

6. Within the range of services provided to adults with disabilities, what are your thoughts on **what would need to be done to achieve an integrated continuum**,

or system, of care which would maximize the use of resources to achieve better care and better health outcomes?

## SECTION 2

### *Questions related to how the system of care for adults with disabilities is integrated with other health and social services*

The following questions relate to the how the services above interact with other major components of the health care system such as acute care hospitals, physicians, and community services such as community health centres, and public health promotion and illness preventative services.

7. a) To what extent do you feel that the set of services for adults with disabilities identified in Question 1 are **integrated with this broader health care sector**? (Hospitals, physicians & community services)
7. b) What are the **strengths and weaknesses** of the linkages with the broader health care sector?
7. c) To what extent do you feel that the set of services for adults with disabilities (Question 1) is **integrated with services outside the health system**, such as social services, housing, transportation and education?
7. d) To what extent are services for adults with disabilities **integrated for informal caregivers** (for example, family members)?
7. e) What are the **strengths and weaknesses** of the linkages with services outside the health system?
7. f) To what extent can **clients move** between types of services and locations of services?
7. g) To what extent is care within the broader context being provided in the most **cost-effective** way (that is, in the most appropriate setting by the most appropriate provider).
8. Within the broader health and social services sector:

- Is it possible to move funds between the system of care for (adults with disabilities) and other components of the broader system (e.g., hospitals, physicians, social services)?
  - To what extent does funding follow the client in the larger health and social service system?
9. a) Within the range of services provided to adults with disabilities, do you feel that there are **gaps** in the availability of services in the broader health and social service system? If so, could you please elaborate?
9. b) Within the range of services provided to adults with disabilities do you feel that there are existing services that are **under-utilized**? If so, could you please elaborate?
10. Considering the larger health and social service system *and* the system of care for adults with disabilities, what are your thoughts on what would need to be done to develop an **overall continuum**, or system of care for adults with disabilities?
- 11.a) **What supports** in other sectors are essential to achieving the best possible system of health and social services for adults with disabilities?
11. b) **What policy initiatives** (if any) would strengthen the interface and level of integration or coordination between the set of services for adults with disabilities and other components of the broader health and social service system?
11. c) Are any of these initiatives underway in your jurisdiction? If so, can you describe the stage at which these initiatives are underway.
12. Are there major contextual issues that currently exist in your region which may help us to better understand your responses to our questions?

Thank you very much for taking part in this interview. If you have any further comments or questions about the research please let me know.

# **Plan d'entrevue téléphonique pour le Projet d'analyse des interfaces du continuum des soins de santé**

## **Soins de santé pour les adultes handicapés**

Merci d'avoir accepté de participer à notre sondage qui s'inscrit dans le cadre d'une importante étude financée par Santé Canada. Les résultats de l'étude fourniront aux décideurs les renseignements nécessaires pour améliorer la manière dont les soins de santé sont organisés et offerts au Canada.

**Les ministères fédéraux, provinciaux et territoriaux de la Santé et des Services sociaux ont demandé de plus amples informations sur des questions pouvant leur permettre de déterminer ce qui constitue un continuum, ou système, intégré de soins de santé pour un certain nombre de groupes démographiques, dont les adultes handicapés.**

**Ce projet a pour objectif d'examiner ce qui constitue un continuum, ou système, intégré de soins de santé pour un certain nombre de groupes démographiques, dont les aînés, les adultes handicapés, les adultes ayant des problèmes de santé mentale et les enfants.**

**Dans cette enquête, nous aimerions que vous répondiez aux questions suivantes :**

- § Quels sont les soins essentiels de santé pour les adultes handicapés et (ou) ceux qu'ils utilisent le plus?
- § Actuellement, ces soins sont-ils bien intégrés dans un système de santé?
- § Ces soins sont-ils bien reliés à d'autres services du système de santé (p. ex., hôpitaux, médecins et santé communautaire et publique), ou y sont-ils mal reliés?
- § Ces soins sont-ils bien intégrés aux services hors du système de santé dont peuvent bénéficier les adultes handicapés (p. ex., services sociaux et hébergement).

**Nous aimerions également que vous répondiez aux questions suivantes :**

- Qu'est-ce qui constitue un système efficace de prestation des soins de santé?

- Le système actuel présente-t-il des obstacles à l'intégration efficace des soins de santé? Le cas échéant, lesquels?
- Quelles solutions proposez-vous pour améliorer le système de prestations des soins de santé pour les adultes handicapés?

Soyez assuré que vos réponses demeureront **confidentielles**, que vous êtes tout à fait libre de participer ou non à ce sondage, et que vous pouvez décider à tout moment de vous retirer de l'étude ou de ne pas répondre à certaines questions. Pouvons-nous commencer le sondage?

### Renseignements de base

Votre nom :

Organisation :

Province :

Région : \_\_\_\_\_

## *Définitions*

***Intégration*** : la combinaison de plusieurs services au sein d'un ensemble ou système; l'interaction entre les soins de santé et les services hors du système de santé. Cela signifie qu'il existe des liens bien définis entre ces services.

***Interface*** : les moyens par lesquels les divers soins de santé et les services hors du système de santé sont réunis ou liés; partage, assouplissement ou atteinte des limites des services.

***Système*** : une série de services et leurs interactions. Les éléments d'un système efficace ont pour objectif commun de répondre aux besoins des adultes handicapés en matière de soins de santé, et d'intégrer les services qui leur sont offerts.

# SECTION 1

## Questions relatives au Système de santé pour les adultes handicapés

Nous vous avons envoyé une liste de catégories de soins dont peuvent bénéficier les adultes handicapés.

1. Actuellement, quels sont les soins essentiels et fréquemment utilisés par les adultes handicapés de votre région? Si vous croyez que la liste est incomplète, quels soins proposeriez-vous d'ajouter?

*Selon vous, les soins que vous ne considérez pas comme essentiels pour l'instant devraient-ils le devenir dans un système intégré de santé pour les adultes handicapés? Précisez.*

2. En général, comment les adultes handicapés accèdent-ils au système de santé?

3. a) Pour les soins précisés à la question 1, quels sont les facteurs qui :

- favorisent l'intégration de ces soins dans un système de santé pour les adultes handicapés?
- empêchent l'intégration de ces soins dans un système de santé?

Les facteurs que vous préciserez pourraient toucher aux grands domaines suivants : pratique clinique, communication relative à un service ou à un ensemble de services, administration, résultats et reddition de comptes, politiques, finances et différences régionales.

b) Dans quelle mesure les soins précisés à la question 1 sont-ils fournis avec **efficacité** (milieu adéquat/rapidité de l'intervention/fournisseurs compétents)?

c) A-t-on **récemment** mis sur pied **des initiatives gouvernementales** visant à améliorer l'intégration des soins dans votre région? Le cas échéant, ont-elles été efficaces?

4. Au sujet des soins offerts aux adultes handicapés précisés à la **question 1** :

- *Ceux qui financent ou fournissent les soins peuvent-ils **répartir différemment les fonds** d'une catégorie de soins à une autre en fonction des besoins de la clientèle?*
- *Dans quelle mesure **les fonds sont-ils liés aux besoins de la clientèle**? Par exemple, si les clients reçoivent davantage de soins à domicile plutôt qu'en établissement, les fonds alloués aux soins en établissement sont-ils transférés aux soins communautaires? Existe-t-il des incitatifs de financement pour certains soins?*

5. a) Croyez-vous qu'il existe des **lacunes** au niveau de la disponibilité des soins offerts aux adultes handicapés? Le cas échéant, pourriez-vous préciser?

5. b) Croyez-vous que certains des soins actuellement offerts aux adultes handicapés sont **sous-utilisés**? Le cas échéant, pourriez-vous préciser?

6. Relativement aux soins offerts aux adultes handicapés, comment pensez-vous qu'il serait possible d'**établir un continuum, ou un système, intégré de soins de santé** qui puissent utiliser toutes les ressources à sa disposition pour assurer de meilleurs soins et résultats dans ce domaine?

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## SECTION 2

### *Questions relatives à la façon dont le système de santé pour les adultes handicapés est intégré à d'autres soins de santé et services sociaux*

Les questions suivantes portent sur la manière dont les soins précisés ci-dessus sont liés à d'autres services importants du système de santé, notamment les suivants : hôpitaux de soins actifs, médecins, soins communautaires comme les centres de santé communautaire, promotion de la santé publique et services de prévention des maladies.

7. a) Selon vous, dans quelle mesure les soins offerts aux adultes handicapés, précisés à la question 1, sont-ils **intégrés à l'ensemble du secteur de la santé** (c.-à-d. hôpitaux, médecins et services communautaires)?
7. b) En quoi consistent **les forces et les faiblesses** de l'intégration des soins de santé à l'ensemble du secteur de la santé?
7. c) Selon vous, dans quelle mesure les soins offerts aux adultes handicapés (Question 1) sont-ils **intégrés aux services hors du système de santé**, à l'instar des services sociaux, de l'hébergement, des transports et de l'éducation?
7. d) Dans quelle mesure les soins offerts aux adultes handicapés sont-ils **intégrés pour les soignants improvisés** (par exemple, les membres de la famille)?
7. e) En quoi consistent **les forces et les faiblesses** de l'intégration des soins aux services hors du système de santé?
7. f) Dans quelle mesure **les clients peuvent-ils passer** d'un programme de soins et d'un établissement de soins à un autre?
7. g) Dans quelle mesure les soins de santé en général sont-ils **rentables** (c.-à-d. les soins offerts dans le meilleur milieu qui soit par le fournisseur le plus compétent)?

8. Dans l'ensemble du secteur de la santé et des services sociaux :
- Peut-on répartir différemment les fonds entre le système de santé pour les adultes handicapés et d'autres services de l'ensemble du système (p. ex., hôpitaux, médecins et services sociaux)?
  - Dans quelle mesure le financement est-il réparti en fonction de la clientèle dans l'ensemble du système de la santé et des services sociaux?
9. a) Croyez-vous qu'il existe des **lacunes** au niveau de la disponibilité des soins offerts aux adultes handicapés dans l'ensemble du système de la santé et des services sociaux? Le cas échéant, pourriez-vous préciser?
9. b) Croyez-vous que certains des soins actuellement offerts aux adultes handicapés sont **sous-utilisés**? Le cas échéant, pourriez-vous préciser?
11. En ce qui concerne l'ensemble du système de la santé et des services sociaux *ainsi que* le système de santé pour les adultes handicapés, comment pensez-vous qu'il faudrait s'y prendre pour élaborer un **continuum global**, ou un système de santé pour les adultes handicapés?
11. a) **Quels appuis** faut-il rechercher dans d'autres secteurs pour assurer le meilleur système de santé et de services sociaux qui soit pour les adultes handicapés?
11. b) **Quelles initiatives stratégiques** (s'il en existe) renforceraient l'interface et le niveau d'intégration ou de coordination entre l'ensemble des services offerts aux adultes handicapés et d'autres services de l'ensemble du système de la santé et des services sociaux?
11. c) Certaines de ces initiatives sont-elles actuellement mises en oeuvre dans votre région? Le cas échéant, pourriez-vous préciser à quel stade sont rendues ces initiatives?
12. Existe-t-il d'importants enjeux propres à votre région dont vous pourriez nous faire part pour nous aider à mieux comprendre vos réponses à nos questions?

Merci d'avoir participé à cette entrevue. Si vous avez des commentaires ou des questions supplémentaires au sujet de cette étude, n'hésitez pas à m'en faire part.



## **Appendix 5: Focus Group Protocols**

### **Generic Questions for Focus Groups for the Analysis of Interfaces Along the Continuum of Care Project for *People Receiving Services***

#### **Preamble**

Thank you for agreeing to participate in this focus group. The focus group is part of a large national study funded by Health Canada. We would like to obtain your views regarding the services that are available for adults with disabilities. Your input is very important because it will help to identify the strengths and weaknesses of the services currently available to adults with disabilities from the perspective of people receiving services. Your input will be used to inform decision makers about what is working well, and what needs some improvement, from the perspective of people receiving health related services.

Participation in this focus group is totally voluntary. You can choose not to participate in the focus group or not to answer any specific questions. No individually identifiable data will be included in the report of this focus group. Your responses will be anonymous.

#### **Questions**

1. What services are you currently receiving?
2. What are the two or three best things about the services you are currently receiving?
3. What are the two or three areas that need the most improvement with respect to the services you are currently receiving?
4. Do you feel that you are receiving the services that you need? That is, are there services that you feel you need which are not currently available because:
  - the services do not exist
  - there are long waiting lines to access service
  - the services are not affordable
  - other?
5. If you need a range of services, how are those services arranged and coordinated? That is:
  - do you have to try to access services directly?
  - is there someone who helps to coordinate services? If so, who does this coordination?
6. Are there any existing program, financial or other rules or policies which you feel get in the way of you receiving the best possible care?
7. What are the top three or four suggestions you have for improving how care services are provided to:
  - you as an individual?
  - Adults with disabilities in general?
8. If you were in charge of providing health services to adults with disabilities and were given new funding, how would you spend the money to improve the system?

# **Generic Questions for Focus Groups for the Analysis of Interfaces Along the Continuum of Care Project for *Family Members of People Receiving Care Services***

## **Preamble**

Thank you for agreeing to participate in this focus group. The focus group is part of a large national study funded by Health Canada. We would like to obtain your views regarding the services that are available for adults with disabilities. Your input is very important because it will help to identify the strengths and weaknesses of the services currently available to adults with disabilities from the perspective of family members of people receiving care services. Your input will be used to inform decision makers about what is working well, and what needs some improvement from the perspective of family members of people receiving services.

Participation in this focus group is totally voluntary. You can choose not to participate in the focus group or not to answer any specific questions. No individually identifiable data will be included in the report of this focus group. Your responses will be anonymous.

## **Questions**

1. What services is your family member currently receiving?
2. What are the two or three best things about the services your family member is currently receiving?
3. What are the two or three areas that need the most improvement with respect to the services your family member is currently receiving?
4. Do you feel that your family member is receiving the services that he/she needs? That is, are there services that you feel your family member needs which are not currently available because:
  - the services do not exist
  - there are long waiting lines to access service
  - the services are not affordable
  - other?

5. If your family member needs a range of services, how are those services arranged and coordinated? That is:
  - do you or your family member have to try to access services directly?
  - is there someone who helps to coordinate services? If so, who does this coordination?
6. Are there any existing program, financial or other rules or policies which you feel get in the way of your family member receiving the best possible care?
7. What are the top three or four suggestions you have for improving how care services are provided to:
  - your family member as an individual?
  - Adults with disabilities in general?
8. If you were in charge of providing health services to adults with disabilities and were given new funding, how would you spend the money to improve the system?