



**AGING AND DEVELOPMENTAL DISABILITIES
STRATEGIC ISSUES FOR SERVICE AGENCIES**

Prepared for the Board of the
Garth Homer Society

by
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December 2009

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INTRODUCTION AND OVERVIEW

This report was prepared for the board of the Garth Homer Society (GHS.)

Located in Victoria, British Columbia, GHS provides day services to approximately 125 adults with developmental disabilities¹ from Victoria and the surrounding Capital Regional District (CRD). Like many agencies, it has to cope with the aging of its client population. In 2007, 17 percent of GHS clients were over 55 years of age. By 2012, more than 40 percent will be over the age of 50 (GHS, 2007, 8). In recent years, the society has begun to adapt its programs to better accommodate the aging of its clients. In particular, GHS has developed a specialized day program for clients with dementia. But given the expected numbers of clients in later life, the GHS board was concerned about looking beyond the immediate programmatic adaptations that might be needed to the *strategic* impact of the aging of its client population – that is, about understanding the implications of the aging of its clients for such matters as GHS’s long-term vision and objectives, overall structure and organizational design, and the scope and scale of needed services and organizational relationships.

The focus of this report is entirely strategic. Its purpose is to briefly outline the issues generated by the aging of the population with developmental disabilities, and to discuss the strategic matters that arise for service agencies as a consequence, with a particular emphasis on day-service agencies. The report is intended primarily as a background document for long-term planning. It is not a detailed review of the body of research on aging and development disabilities, or a guide to the complexities involved in developing and adapting programs and services for older adults with developmental disabilities.

Background research for the report conducted in 2008 and 2009 comprised four activities:

1. *A review of the summary literature on aging and developmental disabilities.* As noted above, undertaking an academic literature review was not within the scope of this project. Instead, it relied primarily on three sources that, taken together, provide a comprehensive summary of both the literature and the practical and policy issues:

Ageing with a Lifelong Disability: A Guide to Practice, Program and Policy Issues for Human Services Professionals, by Christine Bigby (2004)

Ensuring Successful Ageing: Report of a National Study of Day Support Service Options for Older Adults, by Christine Bigby et al. (2001)

Services for Seniors with a Developmental Disability: Literature and Initial Program Review, by Tim Stainton et al. (2006)

2. *Interviews with key informants knowledgeable about aging and developmental disabilities.* These included policy makers, service providers, consultants, and academic researchers. The appendix provides a list of those interviewed.

3. *A brief review of related policy and program initiatives in Canadian provinces.* This included interviews with government representatives in four provinces, and reference to a related policy and program review in all provinces undertaken by Community Services Nova Scotia, Services for Persons with Disabilities.

4. *A survey of current practices in a selection of service providers for people with developmental disabilities.* These comprise a small group of Canadian service providers that

¹ In this report, “disabilities” refers to developmental disabilities.

interview respondents noted for their provision of innovative services for older adults with developmental disabilities.

OVERVIEW OF FINDINGS

1. The current cohort of older adults with developmental disabilities is part of the baby boom. In comparison to earlier generations, this cohort, the first to live predominantly in community care, is living longer – much longer – and its numbers are disproportionately large. In some agencies, more than 50 percent of clients will soon be in later life.
2. As clients age, their needs and interests change, their health and functional abilities decline, and their care and service requirements change. Increasingly, older clients need more expensive one-on-one care and programs separate from those designed for younger people. In this regard, older clients are no different than other older people. However, the current system of community care for people with developmental disabilities has little or no experience caring for clients in later life, and is largely unprepared and not funded to do so.
3. Similarly, the current geriatric care system has little or no experience caring for clients with developmental disabilities and is largely unprepared to do so. For a variety of practical reasons, people with developmental disabilities generally do not do well in long-term care designed for people who do not have disabilities.
4. The gap between the disabilities care system and the geriatric care system is largely an artifact of their separate but parallel evolution, a product of policy. To date, however, neither the health care sector nor the disabilities care sector has provided much response, in the form of policy, to the aging of people with developmental disabilities. Because in the general scheme of things the number of older adults with developmental disabilities will always be small, the issue is unlikely to receive the policy attention or funding it deserves any time soon. The risk of such inattention and lack of funding is increased in the current environment of fiscal restraint. In the near to medium term, service providers will probably need to manage the aging client without significant additional funding.
5. Systemic forces acting on agencies will complicate the management task. In addition to the increasing severity of disability among younger clients, these forces will include instability in residential care for many clients, the presentation for care of older people with developmental disabilities currently not in the system, and changing preferences in care among second- and third-generation decision makers in families. Most significant for stand-alone day-service agencies will be the need for closer integration between day and residential services to meet the needs of older clients.
6. In the review of current practices undertaken for this report, a wide range of responses to emerging geriatric care needs was noted among the agencies consulted. At one extreme were those agencies that have been handling aging clients essentially on a one-by-one, ad hoc basis, doing their best to manage emerging needs as they arise. Other agencies go a little further in developing and adapting individual programs especially for older clients. At the other extreme are agencies that seek to provide comprehensive or integrated geriatric care. A body of standard practice that could be labeled “best practice” in the care of older adults with developmental disabilities is difficult to discern; there is still too little experience within the system of community care for such conventions to have emerged. However, many innovative program ideas exist, and those agencies that found the management of aging clients the least problematic were those that offered a range of residential and day services and that therefore experienced fewer barriers to better program integration for older clients.

OVERVIEW OF PLANNING RECOMMENDATIONS

Because as yet no body of widely accepted best practices for the care of older adults with developmental disabilities exists, agencies experiencing a rapid increase in the number of older clients face strategic decisions. A three-step planning process to help clarify strategic questions related to geriatric care is recommended:

1. *Assessing the potential impact of the increasing numbers of older adults with developmental disabilities.* On the basis of the age distribution of their client group and a number of other factors, such as the disability profile of clients, the depth of staff skills, and the changing preferences of family decision makers, agencies will need to make an assessment of the likely impact of the aging of clients on their own organizations. Agencies will not all be affected equally.
2. *Clarifying the fundamental business questions.* Having assessed the impact, agencies will need to answer these fundamental business questions: Should we provide geriatric care at all, and, if so, what should the limit of that care be, and how far should our geriatric services extend?
3. *Determining the structure of service delivery.* Having decided to provide geriatric care, agencies will need to determine how to structure service delivery. While the actual design of services may be complex, the strategic issues can be framed in the answers agencies develop to four interrelated planning questions:
 - i) What should the scope and scale of our services be?
 - ii) How will we provide good integration between day and residential services?
 - iii) How will we generate the revenue to pay for geriatric services?
 - iv) Which will be more effective – developing services on our own or developing new partnerships for geriatric service delivery?

I – COMMUNITY CARE, POPULATION CHANGE, AND LAGGING POLICY

The purpose of this report is to identify the *strategic* issues for community disabilities service agencies and organizations arising as a result of the aging of the population with developmental disabilities.

While the concerns raised in the report are relevant to all organizations providing services to people with developmental disabilities, special attention is paid here to the impact on organizations providing day services. The immediate questions are not difficult to comprehend. How does the aging of clients affect the design and delivery of programs? What new services will be needed to accommodate older clients? What new skills will agency staff need? What new partnerships might agencies need in order to be able to provide geriatric care effectively? What are the roles of the health care and long-term care systems in the delivery of services for older people who have a developmental disability? Must agencies learn to work with these systems and, if so, how? And so on. These are precisely the sorts of questions that executive directors and boards are already asking themselves as the first of their clients reach later life.

What is increasingly evident, though, is that over time agencies are likely to need more than *programmatic* adaptation to meet the needs of older clients, in part because of the sheer number of clients that will be reaching old age at the same time, and in part because of the systemic forces on the community of service agencies that this will generate. For many agencies, strategic initiatives will be needed.

Strategies in mandated organizations generally are either incremental or transformational. Incremental strategies aim at improvement to and/or growth in business as usual. Transformational strategies aim at a more fundamental change in operations or direction that will enable the organization to deliver its mission more effectively. The two types of strategy are not necessarily mutually exclusive; aspects of each are often blended in a single strategic plan. Typically, organizations will embark on transformational strategies in response to changing environmental forces, or after sustained periods of incremental growth and change have rendered static structures and procedures less and less able to sustain operations efficiently or effectively.

The central point of this report is that for those agencies most exposed to the effects of an aging client base, and particularly for stand-alone day-service agencies, transformational strategies will be necessary. This is because of three interrelated factors:

1. the relatively recent emergence of the community care system as the primary source of services and care for people and families living with developmental disabilities
2. rapid changes in the population of people with disabilities
3. a lagging policy environment

THE COMMUNITY CARE SYSTEM

Today it is the norm in our society for people with developmental disabilities to receive care and services from a system of community service agencies, which often were founded by the families of people living with developmental disabilities, and by others with a strong interest in their welfare. The purpose of these agencies is not only to provide basic care and safety for their clients, but also to help them learn and grow as individuals, and live and work as independently as they can, integrated in the life of their communities. The approach is succinctly summarized in the mission statement of the British Columbia Association for Community Living (BCACL): “Good lives in welcoming communities.” As the association points out on its website (2009),

In the past, individuals with developmental disabilities were often labeled “mentally retarded” or “mentally handicapped.” Many were placed in

institutions, segregated schools or workplaces with little or no pay. BCACL was founded by parents who dreamed of a better life for their sons and daughters. They wanted their children to learn in school, have friends, and be welcome in their communities.

Before the emergence of community care, many people with developmental disabilities also lived sheltered, hidden lives in the care of their families, prevented by stigma, shame, and bias from achieving personal growth or independence.

We tend to forget how recently all this changed. But it was not until the years after the end of World War II that attitudes began to shift and a strengthened system of community care emerged. For example, the Canadian Association for Community Living was not founded until 1958, and GHS not until 1977. Most of the community organizations that today provide the majority of the care and services for people and families living with developmental disabilities were established between the 1950s and the 1970s.

Consequently, the cohort of clients currently reaching later life after a lifetime within the community disabilities care system – largely the demographically over-represented baby boom generation of people living with developmental disabilities – is the first to do so. Until recently, the disabilities care system by and large has had neither the need nor the opportunity to develop the skills and systems required for the provision of geriatric care and, consequently, now finds itself largely unprepared to meet the changing needs of an aging client base just as the highly populous first generation to spend their lives in community care is rapidly reaching later life.

Similarly, the geriatric care system is equally ill equipped to service older adults with developmental disabilities. Quoting a 2005 study, Stainton et al. (2006, 16) point out that

The aging and disability service systems have historically developed in parallel but separate tracks ... despite often overlapping concerns about issues such as affordable housing, public transportation, access to healthcare, long-term care needs, and economic stability.

As a result, the geriatric care system lacks the disabilities-specific skills and experience needed to care for older adults with developmental disabilities. A recurrent theme in the literature is that while the disabilities care system and the geriatric care system share many common concerns, neither is well equipped to provide services to older adults with developmental disabilities. The former lacks skills and experience with geriatric care; the latter lacks skills and experience with disabilities. As Bigby (2004, 50) notes, speaking of Australia but with equal applicability to Canada,

Neither system has a clear responsibility to respond to this group, and neither has developed systematic policy or program structures to guide the responses and delivery of support. Too often older people with intellectual disability fall between the two systems, victims of each system's poor knowledge base about ageing with a disability. They are regarded as "too old" by the disability service system that has too little experience or knowledge of ageing and as "too young" for the aged care system that is geared towards the frail aged and has little experience or knowledge of people with lifelong rather than age associated disability. Possibilities of falling between service systems are heightened in the climate where in both systems demand for services outstrips supply and available resources.

THE CHANGING CLIENT POPULATION

The service gap between the disabilities and the geriatric care systems perhaps would be inconsequential if the number of older adults with developmental disabilities was not increasing rapidly. Due to a number of demographic factors, however, the population of older adults with developmental disabilities is growing quickly. Not the least of these factors is the baby boom. Bigby (2004, 43) states that “the number and proportion of older people with intellectual disability is increasing and will continue to do so until after the baby boom generation moves into later life in 2012.”

That said, the number of older people with developmental disabilities is difficult to ascertain precisely. Both Stainton et al. (2006, 11) and Bigby (2004, 42) point out that assessing population size is difficult, for a variety of reasons. They include:

- inconsistent definitions of disability
- varying definitions of aging
- likely systematic under-reporting of disabilities in survey-based estimates
- the large number of people with developmental disabilities living entirely outside the formal service system, rendering prevalence estimated on the basis of service statistics unreliable
- widely varying estimates of the general prevalence of developmental disabilities

Worldwide, the number of people with developmental disabilities is estimated at approximately 60 million (Stainton et al. 2006, 11) In Canada, the most frequently cited estimate of prevalence is provided by Statistics Canada (2001) in *A Profile of Disability in Canada*, a report derived from data collected in the 2001 Participation and Activity Limitation Survey (PALS). PALS was a telephone survey of 35,000 Canadian adults and 8,000 children selected on the basis of answers to two questions, which were included in the 2001 census, regarding activity limitations. The survey excluded persons living in the Yukon, Northwest Territories, and Nunavut, in institutions, and on First Nations reserves.

A Profile of Disability in Canada suggests that, on average, 0.5 percent of Canadian adults aged 15 years or older have a developmental disability, with the highest rate, 0.07 percent, being among young adults aged 15 to 24, and the lowest, 0.02 percent, being among older persons aged 65 to 74. According to the Statistics Canada report, the difference in reported prevalence between younger and older adults may appear because many of the oldest Canadians with developmental disabilities are still housed in institutions and would therefore not have been counted by the PALS study. The difference may also be due to increasing survival rates of infants with developmental disabilities.

On the basis of the above report, the National Advisory Council on Aging (2004, 3) states that in 2001 there were 44,770 persons aged 45 to 64 with a developmental disability in Canada, and 11,080 aged 65 to 74.

For comparison, prevalence rates Bigby (2004, 32) cites for the United States are 0.4 percent of the population aged over 55, and for the United Kingdom are 0.4 to 0.5 percent of the same age group. Rates for Australia are 0.13 percent of adults aged 55 years or more, and for New Zealand are 1.43 percent of the population aged 51 years or more. *A Profile of Disability in Canada* states that its data on the prevalence of developmental disabilities should be used with caution, suggesting that the data are not highly reliable.

The uncertainty in the numbers is of more than just theoretical interest and is not always simply a statistical issue due to small sample sizes in surveys. Bigby (2004, 42) notes:

Research that has utilized vigorous outreach and case finding strategies suggests that as many as 25% of the older people with intellectual disability are unknown to the disability service systems and thus not included in samples that only draw on service populations.

The Developmental Disabilities Association (DDA) in Richmond related in a communication to the author that its investigations suggest that 33 percent of the people with developmental disabilities in the Lower Mainland are not being served within the disabilities care system. The International Association for the Scientific Study of Intellectual Disabilities (IASSID 2002) states in a fact sheet that

Estimates of people with intellectual disabilities who are living with families run as high as 50%, even in nations with highly developed service networks.

Typically, adults in this category are living with aging parents or other family members. The fact sheet also states that support of families ought to be a policy priority because “the number of adults with special needs requiring services is far greater than the service providers’ capacity to accommodate them.” The strategic issue for service agencies is the unanticipated demand that may arise if, as they age, older people with developmental disabilities who are not being served within the disabilities care system begin to present for service, perhaps because of the changing circumstances of their caregivers who are themselves aging.

Table 1 provides a telling illustration of the potential impact. For the sake of illustration, prevalence rates for older adults are assumed to be more in line with those for the general population in Canada, and with the most used prevalence figures for older adults in the United States and the United Kingdom – somewhere in the range of 0.4 to 0.5 percent. The difference between the two rates is in the range of the percentage of adults with developmental disabilities living outside the service system. The population projections for the CRD are from BC Stats (2007). Table 1 shows that, by 2018, the projected difference in the number of older adults aged 45 and above with developmental disabilities in the CRD at the two rates of prevalence is 331 individuals (the sum of the two figures for 2018 in the “Differences” column in table 1), almost equivalent to the client base of three agencies the size of GHS. For community-level planning purposes, the uncertainty is significant.

Table 1. Uncertain Prevalence of Developmental Disabilities Among Older Adults in the CRD, 2007 and 2018

Age Range	Year	Projected Population	Prevalence 0.4%	Prevalence 0.5%	Difference
65+	2007	63,922	255	319	64
	2018	89,240	357	446	89
45–65	2007	226, 838	907	1,134	227
	2018	241,267	965	1,206	241

Not only are the absolute numbers of older adults with developmental disabilities increasing; so is their life expectancy. We are all familiar with the way in which better health care and improved life and social circumstances have contributed to rapid increases in life expectancy in the general

population of industrial countries during the 20th century. Rapidly increasing life expectancy, combined with the impact of the baby boom, has created the “aging crisis” and its massive impact on health and social services. The changes in life expectancy for people with developmental disabilities have been similar, and perhaps even more dramatic, than those in the general population (Department of Disability and Human Development 2002):

- U.S. data suggest that the mean age at which people with developmental disabilities die was 66 years in 1993, up from 59 years in the 1970s and 19 years in the 1930s. Among people with less severe disabilities who do not have Down’s syndrome, life expectancy is now approaching that of the general population.
- Among people with Down’s syndrome, life expectancy remains lower than among the broader population with developmental disabilities; however, the overall increase is similar. According to U.S. data, the mean age of death of people with Down’s syndrome reached 56 years in 1993, up from an estimated 9 years in the 1920s.
- On the basis of changes in life expectancy and the aging of the baby boom generation, U.S. studies suggest that the total population of people with developmental disabilities aged 55 and over will double by 2030.

Notwithstanding increasing life expectancy, the Vancouver Island Health Authority (VIHA) suggests that, among people in care who have more severe disabilities, the average age of death is currently around 50 years.

THE POLICY CONUNDRUM

From the perspective of strategic issues affecting service agencies, the circumstances outlined above might not be of imminent concern if, in fact, the care for older adults with developmental disabilities was the subject of policy and program initiatives within either or both of the disabilities care system or the geriatric care system. The broad questions that need to be addressed are straightforward: Who has primary responsibility for funding the care of older adults with developmental disabilities? What resources are needed? How should the health care system and the disabilities care system work together in serving older adults with developmental disabilities? However, as noted above in the quotation from Bigby in reference to Australia, to date neither the disabilities care system nor the geriatric care system has assumed policy-level responsibility for older adults with developmental disabilities.

This is certainly also the case in Canada. Health/disabilities care policy managers in four provincial governments – those of British Columbia, Alberta, Ontario, and Nova Scotia – were interviewed during the research for this report. None was able to report any policy initiatives on aging and developmental disabilities, or even that the issue had come up as a matter of concern.

In 2008, Community Services Nova Scotia, Services for Persons with Disabilities published two reports on services for persons with developmental disabilities, one on residential services (2008a) and one on vocational and day programs (2008b). The former report notes that even though the population of persons with disabilities was not growing, the aging of the population and associated high disability rates suggested that service capacity was likely to be an issue for the next 15 to 20 years. Nonetheless, a review of provincial trends across Canada in the same report, while stating that “services to aging individuals are an increasingly complex issue,” found no initiatives or programs of special note with reference to older persons with developmental disabilities.

Bigby (2004, 43) notes,

The implications of these demographics are that the growth of older people with intellectual disability and their demands on support services are likely to be

gradual and manageable rather than overwhelming. The opportunity exists for a planned approach to developing policy and adapting service systems to enable flexible responses to the changing needs of an increasing number of older people with intellectual disability. However, the small numbers also mean the potential exists for their specific needs to be neglected amid demands of larger groups ...

The challenge is that, while the aging of the population with developmental disabilities is a significant issue when viewed from the perspective of the disabilities care system, or from the perspective of a service agency facing a rapidly aging client population and changing service needs, in the larger scheme of things the number of older adults with developmental disabilities is small. *The gradual manageability of the aging of the population that have a developmental disability as a whole is of little relevance to the manageability of services in an agency in which 40 to 50 percent of the client population may be seniors within a very few years.* It seems unlikely, therefore, that policy makers and service providers will share a common view of the issues any time soon. This suggests that the aging of service providers' clients is most likely to remain, by default, a matter for the disabilities care sector to deal with, probably on an agency-by-agency basis. Nor does it seem likely, at the beginning of what will probably be a long period of fiscal restraint, that adequate funding will be made available to help agencies cope with the aging of their clients.

The best guess is that agencies will be on their own for quite some time yet. In Ontario, as Stainton et al. (2006, 17) point out, the Ontario Partnership on Aging and Developmental Disabilities (OPADD), which aims to find ways to get the disabilities care sector and the health care sector working together to support older adults with developmental disabilities, was initiated by senior managers in disabilities organizations precisely because they had concluded that specific funding and policy support would not be forthcoming from government.

II – AGING IN PEOPLE WITH DISABILITIES

In many ways, people with developmental disabilities age much like anyone else. However, due to factors associated with their disabilities, they generally have poorer health and greater need for support, and experience greater health-related functional decline, than do older people without developmental disabilities (Bigby 2004, 46). This is partly because in people with developmental disabilities genetic issues and pre-existing conditions increase both the risk involved in and the impact of aging, and partly because contingent and experiential factors exacerbate geriatric decline. For example, factors such as poor lifestyle, social isolation, reduced access to health care, impaired communication of health issues, disadvantaged socio-economic status, and poor health care in earlier life may all contribute to health issues and decline in later life. In this regard, people with developmental disabilities again are not much different than anyone else; these same factors will contribute to poorer health and functional capabilities in later life even in people without any prior disability.

Some conditions occur in people with developmental disabilities more often than in the general population, for example, thyroid disorders, heart disorders, and sensory impairments. Also, the rate of psychiatric problems among older people with developmental disabilities is two to four times the rate in other older people.

Other age-related health issues are more frequent in people with particular syndromes. The best known are the increased risk of precocious aging, dementia, and increased sensory loss in people with Down's syndrome. Other examples include:

- osteoporosis in women with cerebral palsy due to long-term inactivity
- osteoporosis in people with epilepsy due to their use of medications
- bladder and swallowing problems in people with cerebral palsy
- mitral valve prolapse and musculoskeletal disorders in people with Fragile X syndrome
- diabetes, cardiovascular disease, and obesity in people with Prader-Willis syndrome

Again, like older people anywhere, aging people with developmental disabilities encounter a spectrum of psychosocial changes and support needs involved with the transitions of later life and personal life planning. These include the following:

- increasing social isolation
- changing interests and declining energy
- retirement (which, depending on the individual, may mean retirement from both supported employment and conventional day services, or even perhaps retirement from supported employment into day services)
- cognitive decline
- financial and estate management
- loss of family and friends; grief management
- acceptance of mortality

Older people who have developmental disabilities, like older people generally, need transition planning and support in relation to these issues.

That said, defining a “typical” course of later life for people with developmental disabilities is not really possible. Aging in people without disabilities is readily accepted as being highly variable – some people are “old for their age,” meaning that they exhibit symptoms of functional and health decline years before they are generally expected to, while others remain healthy, able, and cognitively intact well into later life. As is the case in the general population, among people with

developmental disabilities, older people are more heterogeneous in health and abilities than younger people. The implication is that projecting, from the averages, the course of later life is more difficult to do for an older person with disabilities than for a person in the general population. An individual's unique history, special concerns and interests, and individual care plans remain the foundation of care, perhaps even more in later life than in one's younger years.

PERSONS WITH DEVELOPMENTAL DISABILITIES IN LONG-TERM CARE

In principle, there is no reason that older people with developmental disabilities should not be able to fare well in the long-term care system for people without disabilities. This is the view of almost everybody interviewed for this report – consultants, policy makers, researchers, and service providers. What's more, most agencies consulted, whatever their views on aging in place, were able to provide an example of at least one of their clients who had moved on to a long-term care facility and was doing well in the new environment. One agency even built an assisted-living facility that integrated care for persons with and without a disability, and found that integration did not present a problem and was in fact easier than most people had presumed it would be.

However, the literature suggests that for various practical reasons, people with developmental disabilities generally do not do well in long-term care. One reason may be selective bias against people that are perceived to be difficult, and therefore expensive, to care for within a long-term care system in which demand exceeds supply. As one researcher in British Columbia notes, "the current system is not able, not interested, and, quite frankly, unwilling, to accommodate adults with developmental disabilities."

The literature notes a number of other explanations researchers have posited as to why long-term care does not provide a successful care environment for people with developmental disabilities. These include the following:

- lack of knowledge, disabilities-specific skills, and previous experience among long-term care providers
- lack of acceptance and integration of people with developmental disabilities, because often they are younger than the other residents in a long-term care facility
- the social isolation of people with developmental disabilities within long-term care facilities due to the lack of personal experience among the current generation of older people who do not have a disability with community integration of those who do

Another explanation is the simple fact that even for many people who do not have a disability, long-term care is not a positive experience. If people without disabilities often do not do well in long-term care, people with disabilities are unlikely to fare any better in such care.

ONTARIO PARTNERSHIP FOR AGING AND DEVELOPMENTAL DISABILITIES

One example of an attempt to address the gap between the disabilities care system and the long-term care system in a systematic, province-wide way is the OPADD. As noted above, the OPADD was founded by disability agency executives who were frustrated with the lack of funding for the care of older adults with developmental disabilities, and concerned that supportive policies would not be forthcoming from governments any time soon. This initiative promotes and supports local cross-sectoral transition planning for individuals who are disabled – an attempt to get the health care sector and the disabilities care sector working together on a case-by-case, agency-by-agency, community-by-community basis. The OPADD is very focused on the development of practical solutions and has published a number of how-to and resource guides on matters such as information for families of older adults with developmental disabilities, and information on how agencies in both sectors can build an appropriate base of support and care skills. The OPADD's central publication is *Aging with a Developmental Disability: Transition*

Guide for Caregivers (2005). Although it is largely specific to the Ontario context, the guide provides exhaustive checklists of health, psychosocial, and personal matters of concern in the care of older adults with developmental disabilities. It also provides a useful description of the “tipping points” in the lives of clients that warrant a change in support arrangements. The tipping point idea may be useful in helping agencies define their limits of care.

THE CHALLENGE FOR AGENCIES

From an agency point of view, the challenges the aging of clients poses are considerable. Clients are reaching later life in a disabilities care system that has not previously accommodated the elderly and therefore lacks the skills and experience needed to provide that care. The geriatric care system, where the needed geriatric skills and experience are available, is similarly incapable of providing care for people with disabilities. Because of lagging policy, the burden of care for older clients will probably fall by default to the disabilities care sector. For many agencies, older individuals will soon form a large portion of the client population; in one agency consulted, more than 50 percent of residential clients were already over the age of 50.

The challenges to agencies are threefold.

First, of course, they must continue to deliver all the disability-specific services and programs that they have provided all along.

Second, they must find or develop the resources, skilled staffing, and programs to provide geriatric services. For the most part, these are no different than the services that the elderly in the general population need. Depending on how individual agencies define their scope of service, those services include the following:

- health and fitness maintenance
- mental health maintenance and management of increasing cognitive impairments
- accommodation of illness and functional decline
- management of medications
- management and transition planning with respect to retirement, changes in personal interests, and financial and legal matters
- management of grief, loss, and increasing social isolation
- end of life planning and palliative care

Most agencies suggest that they can cope as long as the client numbers are small, though the cost per client of doing so is high. The real issue is how to deliver and pay for such services when the client numbers are large.

Third, because aging in people with developmental disabilities is so variable, agencies will need to provide these services in a way that is flexible and highly accommodating of individual differences and needs. Group programs and models are likely to be less and less applicable as clients age.

III – EMERGING SYSTEMIC ISSUES

It is probably fair to say, at least with respect to the agency managers interviewed, that they tend to see the issues that the aging of the client base generates as purely operational and readily solvable given adequate funding. Give us the resources to pay for proper staffing and program development, they say, and we will be able to cope. A number of executive directors expressed the view that their only real concern in the matter was the lack of adequate funding. Particularly in those agencies that have the operational flexibility that a diverse range of residential, day, and community services provide, and especially if those agencies also provide services for seniors who do not have a disability, accommodation of aging clients is seen as less of a concern and as readily manageable within the breadth of normal operations if only they could be supported by appropriate policy and funding.

For different reasons, some of the policy makers and consultants interviewed as part of the background research for this report echoed this view – that the aging of clients is not a matter of strategic or policy concern. They expressed the view that:

- because of continuing premature mortality in the population with developmental disabilities, especially among people with more severe disabilities, much of the service pressure the aging of clients creates will be mitigated;
- the long-term care system will ultimately accommodate the balance of aging clients; and
- if agencies focus strongly on individual care plans, they will be able to deal with most of the issues arising from aging of clients before they need long-term care.

Although no specific data were supplied, a senior manager from VIHA noted in an interview that, within the authority's jurisdiction, most people with more severe developmental disabilities were still dying around age 50, and that therefore the impact of the aging of the population with disabilities as a whole would remain small. In other words, it would be mitigated by the continuing precocious death of the people for whom care is most difficult. The hidden assumption in this argument is that because people with more severe disabilities are the most difficult to care for when they are young, their early deaths imply that the aggregate burden of care will decline as the population ages; or, to put it another way, because the people easiest to care for are the most likely to survive into later life, their aging should not be problematic, or it least no more problematic than that of a person who has no disability. This argument, however, misses the point; that people are easy to care for when they are young does not necessarily mean that they remain so as they age. That fact is precisely what is at the heart of current concerns about the aging of society as a whole. Increasing survivorship in the broad population is creating the geriatric crisis, and continuing early mortality among some groups does not moderate this.

The other assumption that seemingly underlies these views is that aging will cause no system-level stresses – that all issues arising out of the aging of clients will be dealt with primarily within programs and structures as they already exist in the care network for people with disabilities or within the long-term care system. This is probably not the case, however. The long-term care system has already been seen to be no better prepared to deal with developmental disabilities than the disabilities care system is prepared to deal with aging. In addition to immediate effects on programs, these five emerging system-level issues, which are discussed below, will affect the scope and scale of disability services as they apply to older clients:

1. a need for increased integration of residential and day services for older clients with developmental disabilities
2. increasing demand on the part of elderly adults with developmental disabilities, who have been living entirely outside the disabilities care system, for care for the first time in their lives

3. instability in residential care arrangements when service providers are not able to accommodate geriatric needs
4. changing family preferences relating to care
5. reported increasing severity of developmental disabilities among younger people

At this point, reports on these issues are primarily anecdotal and little firm data exists. Minimally, they merit a watching brief from agencies as they plan.

1. INCREASED INTEGRATION OF SERVICES FOR OLDER CLIENTS WITH DEVELOPMENTAL DISABILITIES

Increased integration of services may well be the single most important strategic concern for developmental disabilities day-service agencies as they plan for the provision of geriatric services. A near universal observation in the research done for this report was that, as clients with developmental disabilities age, much more flexibility and responsiveness are needed in the design and operation of day services to accommodate individual needs. Group programs in which participants are treated uniformly do not suit aging clients well. Specific concerns include the following:

- accommodating clients' widely varying health care and maintenance needs
- allowing for clients' declining energy levels and accommodate a variety of increasing functional and mobility limitations
- allowing for more downtime and rest periods during the day for people who may not have the energy to spend a full day in group programs
- accommodating clients' loss of interest in traditional day programs
- accommodating clients' desire to "retire" from more structured day programs
- providing increasing levels of one-on-one support as clients age

Another nearly universal observation during the research was that these sorts of accommodations are most easily achieved when day programs are closely integrated with residential care so as to minimize transportation requirements, provide access to bed and private space during the day, and provide better access to health care services where available.

In reference to day services in Australia, Bigby et al. (2001, 40) note:

The interface between day support and residential services was commonly mentioned as problematic, particularly when two or more agencies were involved. The achievement of flexibility, spontaneity and shorter hours of attendance/active participation identified as a central feature in meeting older people's needs were consistently seen to be undermined by rigidity in residential programs ... There were exceptions when one agency managed both service types.

In the interviews conducted for this report, even agencies providing both residential and day services noted issues relating to achieving better integration. Some reported initiatives to begin offering day and residential services within a single service environment.

The point is that day services become more difficult to manage as clients age because of their increasingly variable individual needs. They will be most easily managed when day services and residential services can be coordinated. For stand-alone day-service agencies, accommodating such needs is likely to be a major strategic issue.

2. FIRST-TIME PRESENTERS' NEED FOR CARE

As noted above, a significant portion of the population with developmental disabilities lives entirely outside the disabilities care system. Estimates quoted above in the section on the changing client population range from 25 percent to 50 percent of the population with developmental disabilities. The DDA estimates that 33 percent of the Lower Mainland population with developmental disabilities lives outside the system.

In response to these facts, several respondents interviewed raised the idea that many of these people with developmental disabilities either (i) have a disability that is not severe or (ii) are recent immigrants who are members of ethnic communities – the point apparently being that because of reduced care needs in the first instance, or because of a culture of family care in the second, this portion of the population with developmental disabilities is unlikely to become an issue for service agencies.

Most of the agencies consulted, however, agreed that they have already encountered older adults presenting for care for the first time in their life, and that this trend will probably continue. Not all of the people with developmental disabilities being cared for outside the disabilities care system are from ethnic communities or have less severe disabilities; nor is it the case that ethnicity or having a less severe disability means that a person with developmental disabilities will not need care within the disabilities care system later in life. As noted above, that a person's current disability is not severe does not imply that care issues will not emerge as the person ages; to the contrary, it is precisely the greatly increased life expectancy of people with lower levels of disability that will be the source of the increased burden of geriatric care. More to the point, several respondents interviewed said that most adults living outside the disabilities care system are living at home with aging parents. As the care-giving parents themselves age and become less capable of providing support, alternative care will need to be found for the persons for whom they were caring. The assumption should not be made that the second or even third generation of care providers and decision makers within a family, even in ethnic communities, will have the same concerns and interests as the first generation – the parents of the person who has a disability.

As the principal author of the UBC study remarked:

One of the major issues will be transitional planning for older persons with developmental disabilities who are currently living at home with their aging parents. As they become unable to look after their developmentally disabled children, they will have to seek alternative residences.

In terms of a strategic perspective, this represents increased demand for services. People will be presenting for care at that point in their lives when their care needs are the greatest. Agencies will need to consider whether they are prepared to accommodate this unanticipated demand, and how.

3. INSTABILITY OF RESIDENTIAL CARE

As in the case of people with disabilities who live outside the disabilities care system, those living within the care system are likely to encounter a degree of instability in residential care arrangements, due to the inability or unwillingness of caregivers to meet the growing need for geriatric care. The risk of this occurring will be smallest in larger scale, more diverse residential environments where organizations with larger staffs and a broader range of services are more likely to have the means and flexibility to undertake the staff training and skills development needed to provide service to older clients. The risk will be highest for people in family or private home care, or for those living independently or semi-independently, due to the aging of caregivers and the changing client needs that cannot be accommodated, mostly because caregivers lack the appropriate care skills and experience. Most of the agency managers interviewed for this report confirmed that they have observed this starting to happen.

For day-service agencies, instability in residential care is likely to have two sorts of consequences. First, it will make closer integration of day and residential care for older clients more difficult to manage. A number of the agency managers interviewed gave a telling example – the case of private home care providers – noting that for many of them providing residential care is essentially a second job, and day services allow them the opportunity to do their regular work during the day. Because such caregivers are at their workplace during the day, they are therefore unable to accommodate any demand for more flexible integration between day and residential services that may require a level of home care during the day.

Second, it may mean that day-service agencies become increasingly responsible for aspects of personal care – arranging for dental care, for example – that are now delivered in the context of residential care. In effect, if day-service agencies come to have the most durable and stable relationships with older clients, they may by default end up providing additional services to older clients that they do not provide for younger ones.

The extent to which the instability of residential care for older clients affects any individual day-service agency will depend on the distribution of types of residential care among older clients. As noted above, instability is likely to be higher in family care, private home care, or independent living environments than in group care arrangements. It is interesting to consider the issue from a GHS perspective. Table 2, which shows the distribution of types of residential care among GHS clients (GHS 2007, 12) (though not just among *older* clients, which would provide a better picture of possible problems), indicates that a very high percentage of clients reside in care environments that may become unstable as clients age.

Table 2. Distribution of Types of Residential Care Among GHS Clients

Type of Residential Care	% of GHS Clients	Risk of Instability of Care
Family	20	Higher
Private Home Care	46	Higher
Independent	11	Higher
Group	23	Lower

4. CHANGING FAMILY PREFERENCES RELATING TO CARE

The possibility of changing family preferences relating to care for older clients is an issue that arose only indirectly in the research for this report. The issue was not noted in the literature review, and none of the individuals interviewed mentioned it directly. However, several managers in agencies that provide group long-term care noted that families of their clients are very happy with the safety and security that the arrangement for their older family members with developmental disabilities provides; this suggests that safety and security are of greater importance to families than continuing efforts to increase clients' independence and integration into the broader community.

The introduction to this report noted that many of today's community care and community living agencies were founded by parents or relatives of children with developmental disabilities who wanted to create a network of services that would support the personal growth of their children and help them gain acceptance and live as independently as possible in their communities. The

potential issue that the interviews revealed is that, as clients age, so do their families, and the key family decision makers in matters of care are likely to change. Will family preferences relating to care change as the caregivers themselves age and their duties perhaps are passed to younger family members of the next or even third generation, who for various reasons (e.g., they live far away or are not blood relations) have different priorities for care? Will concern for independent community living and personal development be replaced by concern for secure care as clients age, the potential for individual growth diminishes, and family duties are transferred?

Very little is known about this potentially significant issue. Its impact may be considerable, given the move to individualized funding, which will introduce a market dynamic into the provision of disability services and could change the patterns of demand for different sorts of services. The possibility that the preferences of family decision makers will change is strong and certainly worthy of attention at the level of both policy and planning in individual agencies. In their planning, at a minimum agencies need to be aware of any transfer of decision-making authority in the families of their clients.

5. INCREASING SEVERITY OF DEVELOPMENTAL DISABILITIES AMONG YOUNGER CLIENTS

This final systemic issue does not arise as a result of the aging of clients. It is a separate, health-related demographic matter, but nevertheless agencies should consider it in any planning they may be doing relevant to the aging of clients. Repeatedly, agency managers interviewed for this report stated that they believe that the severity of disabilities is increasing among younger people with developmental disabilities. As examples, managers interviewed cite increases in the prevalence and severity of autism, Asperger's syndrome, and multiple disabilities in an individual. Although the issue of the increasing severity of disability does not seem to have been researched, one researcher noted that the literature does comment on it. Despite the lack of data, many agencies confirm it on the basis of their experience and offer various conjectures about why it is occurring – everything from the increasing survivorship of anoxic prematurely born infants to the excessive administration of drugs to newborns. While these causes are not certain, their impact for agencies is clear. Now that the first generation in community care is reaching later life, a spike is occurring in the degree of severity of disabilities at both ends of the age spectrum among those in care. Agencies will need to consider this issue in any strategic deliberation about how to manage the aging of clients.

IV – SURVEY OF CURRENT PRACTICES: SERVICE VIGNETTES

As noted in earlier sections of this report, an important part of the background research for it involved short interviews with senior representatives of a small group of service agencies who were identified in discussions with other key informants, or by email inquiries, as providers of innovative services to older adults with developmental disabilities. The people interviewed were mainly executive directors of their agencies or other senior staff persons. The interviews focused on their perceptions and understanding of issues relevant to the aging of clients, the ways that it had begun to affect their organizations, and the ways in which their organizations had begun to respond in terms of policies, programs, and strategies. The purpose of the interviews was to help obtain an understanding of the range of practical and strategic responses to issues to do with aging.

Representatives of eight organizations were interviewed:

- Developmental Disabilities Association – Richmond, British Columbia
- SKILLS Society – Edmonton, Alberta
- Powell River Association for Community Living – Powell River, British Columbia
- Reena – Toronto, Ontario
- Community Living Victoria – Victoria, British Columbia
- Semiahmoo House Society – Surrey, British Columbia
- Christian Horizons Ontario – southern Ontario
- Community Living Campbell River – Campbell River, British Columbia

For the most part, the respondents participated in the interviews with interest and enthusiasm and were quite frank about the problems their organizations are facing. Clearly, most respondents had been pondering the issues related to aging for some time. While the conversations ranged over many points of view and varied initiatives and programs, most or all of the people interviewed agreed on a number of core points:

- Current policy and funding models do not accommodate the needs of older clients with developmental disabilities.
- Unless a change occurs in funding, agencies will need to fundraise privately to meet geriatric care requirements. More than one executive director stated that the alternative is bankruptcy. This view may be overdramatic, but the provision of geriatric services is definitely having considerable financial impact in many agencies.
- The core issue is to be able to accommodate functional decline, manage increasing health issues, and provide for in-service health care and maintenance.
- Conventional day-service models really do not suit older clients; more flexibility, individual planning, and downtime are required.
- As clients age, the best model – given the flexibility needed – is day services much more closely integrated with residential care. Agencies that provide a broad range of services are more able to achieve this.
- Many older people with developmental disabilities not currently being cared for in the disabilities care system will present for care as they age. Most of the respondents stated that their organizations had already begun to experience this.
- Many residential care arrangements for older people with developmental disabilities will become difficult or unstable as clients age because of the care providers' lack of experience, training, and skills in geriatric care.

- Individual transition plans for aging clients are essential. Some respondents suggested – as does the OPADD – that transition plans for such clients should be initiated when they are as young as 40 years of age.

Together, the following short vignettes provide a picture of the range of current programmatic responses to aging issues.

DEVELOPMENTAL DISABILITIES ASSOCIATION

The DDA serves approximately 2,000 clients in Vancouver and Richmond, providing community, family, day, and residential services to both children and adults. An “enterprising non-profit,” the DDA runs several commercial businesses, including soliciting donations of clothing and bottles for recycling in order to raise money to fund the services it provides. At the time of the interview, 50 percent of the DDA’s residential care clients were over 50 years of age; hence the organization’s concern about developing programs for geriatric care.

Over the past few years, the DDA has focused on trying to get projects funded to integrate health services more effectively into disability care. Much of this effort has been centred on attempting to obtain funding to hire health service providers, such as nurses and physical therapists, to work with clients in the context of disability care. At the date of the interview, all of the DDA’s proposals for such initiatives had been turned down. Managers at the DDA tend to see the lack of appropriate, specific funding for older adults with developmental disabilities as a primary problem. They believe that if funding were available, they would not have any issues in developing the needed services. The executive director noted that the cost per client for geriatric care, especially when there are many health issues to be dealt with, can be very high, and that some agencies might actually go bankrupt trying to cope with the aging of clients.

The DDA agrees that to effectively provide services for older adults, day services must be more closely integrated with residential care, and the organization is starting to move its programs in that direction. It has also built a facility specifically for older clients with dementia.

DDA policy is to continue to provide services to clients up to but not including palliative care.

SKILLS SOCIETY

The SKILLS Society provides a range services for both children and adults with developmental disabilities in Edmonton. It currently serves about 400 clients, 51 of whom are aged 50 and above. The society is expecting this number to increase. It has developed an innovative long-term care model for older adults in which progressive care seniors housing is offered in a group, or “pod,” of six self-contained contiguous suites inside a larger long-term care facility for seniors. The suites are full apartments containing both a kitchen and living room. One of the suites is modified to function as a service/care centre; in it, disability support services are provided 24 hours a day in three staff shifts. The others suites are adapted for residents with developmental disabilities, including married couples. The SKILLS Society provides all its disability-specific services on-site, but it also take advantage of nursing care that the seniors long-term care facility provides if it is needed. The average age at intake into the suites is 50 to 60, and residents are able to stay in their suites until the end of life. The initial pod has been a success and the SKILLS Society is planning to expand the model. The toughest issue for the society is the integration in the facility of clients who have a disability with the residents who do not.

POWELL RIVER ASSOCIATION FOR COMMUNITY LIVING

The Powell River Association for Community Living (PRACL) has developed a specialized day service for older adults, the Free Spirit Leisure Club. Although the program is designed for 10 participants, currently it has 13 and maintains a waiting list. The key issue on which the program focuses is the deteriorating health and declining functional abilities of older clients. As clients

age, they may lose interest in the day programs in which they have been participating, and functional and health changes may prevent them from participating in programs and activities designed for younger people. Both health and functional abilities can decline rapidly in older people with developmental disabilities, and one of the key challenges that agencies must prepare for is rapid geriatric change in their clients. Among other initiatives, PRACL has launched the provision of personal health maintenance activities and services within the Free Spirit program. The association would like to be able to hire nurses to deliver this aspect of the program but cannot get the necessary funding. The program provides, by means of volunteers, a high level of one-on-one support. PRACL stresses that, as clients age, their needs and interests change, older individuals require much more downtime than they would get in programs for younger adults, and day programs become more and more like simple daycare as people age. Generally, PRACL continues to serve clients up to the point at which they need palliative care.

Because PRACL offers a range of services, including both day and residential care, it can manage a degree of flexibility within the day program through closer integration with residential care. Practical issues, however, are often a barrier to more effective integration of the association's programs; mobility and transportation are significant limiting problems, and PRACL has difficulty coordinating with private care providers who are unavailable during the day.

REENA

Reena provides a range of comprehensive disability services, serving approximately 3,000 clients, predominantly in the Jewish community in north Toronto. Currently, Reena provides stand-alone day services to about 150 clients. The organization finds that aging becomes an issue in its programs because of the need for them to be more flexible and better coordinated with residential services. In 1998/99, 35 percent of Reena's residential care clients were aged 50 or more, and so the organization decided to begin building small-scale group eldercare homes as a way of accommodating the needs of older clients. Reena's approach to providing care is a pragmatic one, and the organization is not strongly committed to the idea of aging in place. Reena respondents also noted that the families of older clients often appreciate the security of the eldercare environment. In its specialized disabilities eldercare homes, Reena maintains clients until progressive geriatric problems mean that individual health support funding provided through the Ministry of Health is no longer sufficient to provide the level of care needed. At that point, clients are moved into regular long-term care.

When Reena first embarked on its eldercare homes program, it was unable to get funding for the construction of the facility through the Ministry of Health and had to raise the needed funds. Because of the difficulties with the ministry, the CEO of Reena helped found the OPADD, in order to work out ways in which the disabilities care sector and the long-term care sector could learn to work together.

Reena has completed construction of three eldercare homes for adults with developmental disabilities. It is also participating in the development of a 20-hectare integrated "campus of care" north of Toronto, on which various Toronto-based Jewish community service agencies will co-locate facilities.

COMMUNITY LIVING VICTORIA

The oldest and largest provider of community living services on Vancouver Island, Community Living Victoria (CLV) provides day, residential, and community services to more than 200 clients in the CRD. Strongly committed to the principle of aging in place, CLV provides continued support and services through palliative care to the end of life; it does not have an age or functional limit for the provision of care to older clients. What CLV sees as the older style of centralized day programs, which evolved from sheltered services, may not be appropriate for older clients because of their need for greater flexibility and individual support in programs. To

mitigate this, CLV is trying to develop or improve partnerships with community services for seniors. Its view is that, as clients age, the need for interagency case management and the sharing of skills among agencies will increase.

Currently, while the number of CLV clients is small, the organization is managing its services for them on an individual basis – finding and funding services and support as individual needs arise. According to CLV, this approach is unsustainable over the long term, given the number of older clients that will need to be accommodated.

SEMIAHMOO HOUSE SOCIETY

The Semiahmoo House Society is a provider of group homes, independent living support, family support, day services, and personal growth/development programs in Surrey. The society has found that, over time, older adults with developmental disabilities tend to lose interest in the day programs in which they were previously involved and have greater need for individualized services. In addition, as the number of older clients increases, their reduced mobility and tolerance for noise, higher risk of injury, and changing interests were affecting the society's ability to manage programs. As a result, the society established a separate seniors program within its day services. Located in a quiet, more accessible location, the program is staffed by specially skilled service providers who accept that seniors may not want to be "engaged." The society suggests that staff may have difficulty changing their ideas about what services and programs they ought to provide to better meet the needs and interests of older clients. The toughest challenge for the society is coming up with programs that are creative and meaningful for older adults.

Though the Semiahmoo House Society recognizes the need for improved, flexible integration of day services with residential care, it has not attempted such integration because of practical problems, largely difficulties with transportation arrangements. The society also notes that because of the lack of appropriate skills and training for caregivers, many current residential care programs may not be able to meet seniors' needs.

CHRISTIAN HORIZONS ONTARIO

Christian Horizons Ontario is the provincial branch of a global organization that provides day services, community residences, independent living support, and family support to clients both with and without a disability. The Ontario organization has initiated a number of programs that attempt to make disabilities day services more adaptable to individual needs. Its initiatives depend in part on the organization's comprehensive suite of service offerings and its ability to coordinate diverse services within the range of services. For example, Christian Horizons Ontario is locating developmental disabilities day programs within regular geriatric long-term care facilities so that available health services can be called on as needed. In Toronto, the organization took an entire floor of a long-term care facility and integrated its disability programs with those of the facility. Christian Horizons Ontario is also integrating disabilities day services with a regular seniors day-service program. In Elmira, a rural town in southwestern Ontario, the organization is attempting to create a complete continuum of care for older adults with developmental disabilities in eldercare homes composed of 12-person residential care units. The organization has no predefined cut-off point for the provision of geriatric care; it makes its decisions one client at a time on the basis of individual assessments and an evaluation of the organization's ability to provide appropriate care. Christian Horizons Ontario has learned that it needs to develop more flexibility for clients in its day-service program, and that this is particularly difficult for clients who have no access to residential care during the day. They note that older people with developmental disabilities, who are in need of care for the first time in their lives, are seeking it from Christian Horizons Ontario.

Generally, the view of Christian Horizons Ontario is that OPADD-style cross-sectoral coordination works for only a small portion of clients, and therefore the organization works to provide all care from within its own broad range of services.

COMMUNITY LIVING CAMPBELL RIVER

Community Living Campbell River serves 300 clients – children, adults, and seniors – with a broad range of day and residential services. Ten years ago, the organization took the opportunity to partner with VIHA and BC Housing to build a 54-bed assisted-living facility for seniors. Five units in it are dedicated to older adults with developmental disabilities. In the ensuing years, the organization has found that integrating people with developmental disabilities into a non-disabilities long-term care environment is not as difficult as is often supposed, and observes that the care needs of people with and without disabilities tend to converge as people age. The organization reports that it has not had difficulty integrating clients with developmental disabilities into the facility, and that the other residents accept them.

Respondents from the organization noted, as did all other people interviewed, that older adults with developmental disabilities have been presenting for care for the first time in their lives, and that residential care arrangements can become unstable as people age.

V – PLANNING RECOMMENDATIONS

This report has attempted to paint a picture of the way that the aging of people with developmental disabilities will begin to exert different sorts of pressures on the agencies that care for them. One thing is clear: not all agencies will be affected equally. Those that have few clients entering later life will most likely be able to manage their cases on an individual basis in the context of existing programs. This is how many agencies are already coping – with a purely operational response. It may be costly on a per-client basis, but it will be considerably less costly than trying to develop new programs and services, train staff, and adapt the agency as a whole to accommodate geriatric care if only a small minority of clients are likely to need it.

However, many other agencies, perhaps most, will not be in this position; due to increasing life expectancy and the aging of the baby boom generation of people with disabilities, geriatric clients will soon constitute a large portion of agencies' client populations, and will do so for many years to come. Often agencies in this position respond operationally as the first few of their clients reach later life. As several executive directors who were interviewed pointed out, this is not sustainable; the cost per client of ad hoc responses is simply too great. Agencies facing this situation will need to think and plan *strategically* about how to adapt to demographic change; they will need to consider how the scope and scale of their service operations and staffing; the breadth of their partnerships, organizational relationships, and revenue generation; and supporting management, administrative, and governance structures may need to change in order for them to provide geriatric care effectively.

Agencies beginning to plan their response to the aging of clients can frame the strategic questions in three steps:

1. assessing the potential impact of aging clients
2. clarifying the fundamental business questions
3. determining the scope and structure of service delivery

1. ASSESSING THE POTENTIAL IMPACT OF AGING CLIENTS

The aging of their clients will not affect all agencies in the same ways. As noted above, while the aging of people with disabilities may be a small matter from a policy perspective, it could be a very large one for individual organizations. The salient strategic concerns will be driven by a combination of factors that may vary widely from agency to agency, even where a general concern about the aging of clients is shared. Therefore, the starting point for any agency wanting to plan for the impending aging of their clients will be an agency-specific assessment of the ways in which demographic change will affect their own operations and services. The sheer number of older clients, while a central concern, is only one of the concerns. Briefly, the key issues for consideration are as follows.

- *Age distribution of clients.* How many clients does the agency have in each age range – how many baby boomers? how many younger people? What is the average age on intake – how many older adults are presenting for care? Based on the distribution of age, when are geriatric issues likely to become pressing or critical? What is likely to have the greatest impact on services – the aging of older clients or the increasing severity of the disabilities younger clients have? Given the age distribution of existing clients, how rapidly is the impact of aging on services likely to be felt? Will it develop slowly, or are the impending changes likely to come suddenly, within a few years?
- *Disability profile of clients.* How many clients have Down's syndrome? How many clients have disabilities associated with specific geriatric health issues? How many clients have a severe disability, and how many have a less severe one? Because of continuing premature

mortality among people with severe disabilities and Down's syndrome, agencies with a large client cohort of older adults who have a *less* severe disability are likely to experience the greatest impact from aging over the longer term, as contradictory as that may seem, simply because people with less severe disabilities or who do not have Down's syndrome are most likely to have an extended old age.

- *Scope of existing services.* Can expected older clients be accommodated within the existing structure of services by means of simple program adaptation, or will structural changes be necessary? For example, do the current scope and structure of services allow for better integration of day and residential care? If not, what sort of changes will be necessary? What are the barriers to better integration? Are solutions to them as simple as more flexible transportation, or do solutions involve more complex questions of interagency working relationships? Similarly, do the current facilities allow for the physical separation of services for seniors programs if necessary? How will the emerging health and psychosocial needs of older clients be met?
- *Residential care status of clients.* How many older clients are receiving residential care services from agencies that may not be able to provide appropriate geriatric care? What impact is this likely to have? How many clients are living in residential care arrangements that are likely to become unstable as they age?
- *Preferences of family decision makers.* Have the clients' key family decision makers changed? Are parents and siblings still alive and active in care decisions? Have family preferences relating to care changed or are they likely to? Agencies should perhaps be tracking family preferences as closely as they track care issues.
- *Current staff capabilities.* Do agency staff have the knowledge and skills to provide appropriate care for older clients? Does the agency have the staff or volunteer capacity to provide increased levels of one-on-one care if necessary? How can health maintenance needs be met?
- *Service expense.* How are the changes implicit in the questions above likely to affect costs? Many of the people interviewed for this report indicated that, as clients age, the cost of serving them increases.

Despite the uncertainties inherent in the individual variability of aging and in the likelihood of emerging demand for services from people not currently in care, it will be critical for agencies to do their best to maintain an ongoing analysis of the probable impact of demographic change on their operations, both for the practical purposes of year-to-year program planning, and to help frame the longer term strategic issues.

2. CLARIFYING THE FUNDAMENTAL BUSINESS QUESTIONS

Care agencies, having conducted an assessment of the likely impact of aging on their operations, will need to answer two related fundamental strategic questions: Given the projections of the likely impact, can or should agencies be in the geriatric care business at all? If so, what are the limits of the care that agencies will provide?

i) Can or should agencies be in the geriatric care business? It is very unlikely that many agencies will decide that they cannot provide care for older clients. Given the tremendous levels of commitment to clients evident in the sector, most agencies that serve adults will expect to continue to provide services to people with developmental disabilities, age notwithstanding. Moreover, many, though not all, agencies are ideologically and practically committed to "aging in place" – that is, to providing services that allow older adults with developmental disabilities to continue to be cared for in their familiar environments to the end of life or near the end of life, regardless of clients' deteriorating health or functional decline.

Given the increased and changing demand for services that the aging of clients will cause, it would not be surprising for the boards of at least some agencies to decide that they should not be in the business of providing geriatric care at all. For example, an agency with relatively few people reaching later life could decide that it cannot afford to develop geriatric services and capacity for only a small number of clients, and that they might best be served elsewhere. A stand-alone day-services agency, to take another example, might decide that it is unable to provide the needed flexibility through better coordination and integration with the variety of residential care providers also serving its clients. There are many possible reasons why a developmental disabilities organization could decide, quite reasonably and responsibly, that it should not provide geriatric care.

The challenge for agencies involved in deciding whether to provide geriatric care will be to define the age-related limits of care. Doing so will not be simple. Given the tremendous variability of age-related changes among adults with developmental disabilities, a simple age-in-years limit will not suffice and would probably not work in any case.² Most likely a limit would need to be defined in terms of some sort of individual functional or health assessment. Even then, agencies would still need to be prepared to respond to the rapid onset of geriatric conditions in clients, and would need to be able to provide appropriate services until suitable alternative care arrangements could be found, which might not happen quickly. For agencies to simply define themselves as out of the geriatric care business will not necessarily be an easy decision.

Of greater concern will be the impact on other agencies within the care network in a community of agencies' making the decision not to provide geriatric care. Even though few agencies will take this path, those that do will cause an increase in demand for geriatric services within a system that will already be facing unexpected demand from other sources, such as the presentation for care in later life of people who have previously received disability services.

Alternatively, some agencies may decide to become specialists in geriatric care for people with developmental disabilities, although this has not yet been observed. Some agencies may be forced in this direction by circumstances, but others may decide strategically to develop such a specialty. Specialist services exist for young people with developmental disabilities, as do specialist geriatric services for people without disabilities, so why not for older adults with developmental disabilities? For some agencies, offering such services might represent a significant opportunity for business and organizational development.

ii) What are the limits of the care that agencies will provide? Once an agency affirms that it will be in the geriatric care business, it will still need to make a strategic and policy decision on what the limits of that care should be. Again, making such a decision is not necessarily easy to do and, once it has been made, depending on the availability of other services in the community, complying with it may be difficult. The decision will be closely related to the agency's service model and scope of services.

The survey of current practices above noted the following different ways in which the agencies consulted define the limit of services for themselves:

- end of life (the CLV)
- up to but not including palliative care (DDA)
- end of sustaining funding (Reena)

² The author is familiar with another disabilities organization that has tried to maintain a strict age-based upper limit to care. Typically, nothing at all happens when a client reaches the age limit; practicality trumps policy every time in this case. Clients tend to be moved only when the agency reaches the absolute limits of its ability to provide appropriate care.

- individual assessment (Christian Horizons Ontario)

Once again, it must be noted that the decision on the limits of care is strongly related to views and policies on aging in place. Those agencies that strongly advocate community integration also tend to strongly support aging in place and the provision of care within the disabilities care system up to and through palliative care to the end of life. They tend to view provision of geriatric care for people with developmental disabilities in a group care setting or within the long-term care system as attempts at “re-institutionalization.”

Other agencies tend to take a pragmatic view, pointing out that group geriatric long-term care is often the solution for the general population, so why is it not the same for older people with developmental disabilities? These agencies also suggest, as noted above, that once clients reach later life, horizons for personal growth are diminished and family decision makers may therefore prefer security in care over continued efforts at community integration and acceptance.

Clearly, strong feelings and considerable mutual skepticism about this issue exist within the community of care providers. This situation is more than a purely theoretical matter; strategically speaking, it is of practical concern. As the number of older adults with developmental disabilities continues to grow, agencies – particularly smaller agencies and stand-alone day-service agencies – are likely to be increasingly pressured to form partnerships for service delivery. The ability to negotiate and form effective working partnerships will be impaired by ideological and policy differences on aging in place.

3. DETERMINING THE SCOPE AND STRUCTURE OF SERVICE DELIVERY

Within the business model and broad limits of service that each agency defines for itself, it will need to work out how geriatric services will be delivered. To this point, no consistent single set of program and business best practices has emerged for the care of older adults with developmental disabilities. Given the variability among agencies and their client populations, projecting a single optimal delivery model is difficult. Agencies will need to learn as they go what works best for their own particular circumstances.

Those agencies with relatively few older clients will remain able to provide care and services on what is essentially an ad hoc basis, though as noted in the discussions with service providers, the cost per client of such care tends to be high. In a number of instances, such as the Free Spirit Leisure Club in Powell River or GHS’s own program for clients with dementia, agencies have developed programs for small number of clients. It is worth noting, however, that given the individual variability in older clients and the broad scope of geriatric care requirements, even programmatic delivery for small numbers of clients is likely to remain essentially ad hoc and expensive. Many agencies that have a small number of older clients will have difficulty providing consistently and competently the additional range of services needed in geriatric care, if only because making the investment in staff and program development for a small number of clients will be hard to justify. This will be mitigated in agencies that provide both day and residential services, or that also provide services to seniors who do not have a disability. The difficulty will be more pronounced in stand-alone day-service agencies. Initiatives such as the OPADD also help to make service delivery manageable when client numbers are low.

Solutions such as that of the OPADD, which are based on service-level partnerships between disabilities and seniors agencies on a *client-by-client* basis, seem less likely to be manageable and effective once the number of clients increases. At some point, developing geriatric programs from the ground up becomes more effective than continuing to manage the many partnerships needed to sustain programs that are essentially built around individual clients.

While the overall complexity of developing geriatric services is high, the question of an overall organizational strategy for the delivery of care to older adults can be worked out in the context of answers to a relatively small number of interrelated questions on four key strategic issues:

i) What should the scope and scale of an agency's services be? For some agencies, it seems clear that the number of older clients will be large enough to prompt consideration of fundamental changes in the structure of services and the business model. This undertaking involves several key issues:

- developing the staffing and the expertise for geriatric care
- physically accommodating geriatric programs that may need to be separated from other programs
- maintaining the flexibility and redundancy in services and the capacity to deal with rapid changes in health and functional abilities in older clients, shifting residential care arrangements and family preferences, and increased demand from older clients just entering the community care system

Managing these issues is likely to prompt reconsideration of both the scope and scale of overall services. Given fixed capacity, other programs may need to be decreased or eliminated in order to accommodate geriatric clients. With the growth of geriatric programs, some agencies may begin to position themselves strategically as specialist service providers rather than generalists, as most agencies are currently designed. Conversely, the capacity for geriatric care may come from expansion rather than the redistribution of resources. What seems certain is that in most cases, the overall service mix of agencies will begin to shift as more resources are applied to older clients.

ii) How will the agency provide good integration between day and residential services? One of the key issues noted above in effective provision of geriatric care is closer, flexible working integration of day and residential care services. Concerns about integration are minimized in those agencies providing both day and residential care, though many operational problems, such as transportation, may remain. For stand-alone day services, the issue of integration will be particularly acute and will be aggravated by unstable residential care arrangements for older clients. The difficulties will raise the question of expanding the scope of services to residential care in order to become a comprehensive provider of geriatric services, or partnering more closely with other agencies to develop a service solution.

iii) How will the agency generate the revenue to pay for geriatric services? Given the currently restrictive fiscal environment, the policy gulf between the disabilities and health care systems, and the sharply differentiated impact of the aging of people with developmental disabilities on policy makers and agencies, assuming that funding will expand proportionately to cover geriatric services is ill advised. Agencies that have essentially been providers of contract services will suddenly find themselves needing to generate alternative and additional sources of revenue if they make a commitment to the provision of geriatric care. Partnerships may reduce the need for increased revenue but are unlikely to eliminate it.

iv) Will developing services on its own be more effective for an agency than developing new partnerships for geriatric service delivery? The abiding question through all these strategic considerations is whether it will make more sense for an agency to attempt to develop geriatric services on its own or build geriatric services through partnerships. Partnerships can be at a service level or a strategic level. They can also be with other developmental disabilities service providers, or with providers of general populations seniors services.

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APPENDIX: LIST OF INTERVIEWEES

Alanna Hendron, Executive Director, Developmental Disabilities Association (Richmond, BC)

Angel Cardinal Milton, Christian Horizons Ontario (southern Ontario)

Bev Hill, SKILLS Society, Edmonton (Alberta)

Dalia Magrill, Coordinator for the Older Families Initiative, Foundation for People with Learning Disabilities, (United Kingdom)

Danielle White, Director Adult Group Homes, Developmental Disabilities Association (Richmond, BC)

Deborah George, board member, Pacifica Housing (Victoria, BC)

Dr. Brian Plain, consultant on disability issues, Vancouver Island Health Authority

Dr. Mathew Janicki, Associate Director for Technical Assistance, Rehabilitation Research and Training Center, University of Chicago

Ellen Tarshis, Executive Director, Community Living Victoria (BC)

Greg Hill, Executive Director, Campbell River Association for Community Living (BC)

Jennifer Baumbusch, Assistant Professor of Nursing, University of British Columbia

Josh MacDonald, Community Services Nova Scotia, Services for Persons with Disabilities

Judy Hickling, Powell River Association for Community Living (BC)

Keith Pennock, former executive director, Glendale Lodge (Victoria, BC)

Leah Wilson, Research Coordinator, Community Living Research Project, University of British Columbia

Melinda Heidsma, Executive Director, AiMHi – Prince George Association for Community Living (BC)

Mia Oberlink, Project Director, Center for Home Care Policy and Research, Visiting Nurse Service of New York

Michael J. Kendrick, consultant on disability issues, Kendrick Consulting International (North Carolina)

Paul Sankey, Developmental Disabilities Association (Richmond, BC)

Paul Wheeler, Executive Director, Semiahmoo House Society (Surrey, BC)

Paula Grant, Director of Quality Assurance, Community Living BC

Professor Joav Merrick, National Institute of Child Health, Jerusalem

Ron Coristine, Project Manager, Ontario Partnership on Aging and Developmental Disabilities

Sandy Keshen, Chief Executive Officer, Reena (Toronto, ON), founder of Ontario Partnership on Aging and Developmental Disabilities

Shirley Milligan, Semiahmoo House Society (Surrey, BC)



Tammy Khan, Executive Director, Independent Living Housing Society (Victoria, BC)

Terry Schenkel, Assistant Director Family Support, Developmental Disabilities Association (Richmond, BC)

Tim Stainton, School of Social Work, University of British Columbia

Tim Weinkauf, Senior Manager, Program Quality and Evaluation, Seniors and Community Supports, Province of Alberta